

Report on the CLLSA Bournemouth Conference, 18 May 2019

“The opportunity to meet others with CLL was extremely valuable.”

“Consistently high quality of presentations, one of the best conferences overall.”

“Our Under 60's group, launched at Bournemouth, set up a WhatsApp and are now in nearly daily contact with each other - long may this continue - the best outcome of the day for me.”

Our Bournemouth Conference set up new records. We had 106 in attendance. A Saturday event enabled local CLL consultant specialists and a clinical trials nurse to participate for the full day. Our younger members were free to attend without having to take a day off work. The group discussions were rated more highly by attendees than any other aspect of the Conference.

This Report is based on all the feedback we received. It is for:

- Our five expert speakers
- Our four patients and a care partner who told their CLL stories
- Our CLLSA trustees and coordinator
- Our discussion group facilitators
- The 61 CLL patients and their 31 care partners who attended
- The five national and local support and charity reps, who had stalls at the event
- Anyone who is interested in CLL Support Association conferences

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 feedback returns: scores and comments
- Appendix 3: Answers to the unanswered questions from group discussions
- Appendix 4: Tips for coping with living with CLL, volunteered by discussion groups
- Appendix 5: The Programme for the Conference

What worked well

- The good partnership between the Royal Bournemouth Hospital's CLL team and CLLSA
- A well thought-through sequence of items on the programme
- The unusually high attendee satisfaction with the discussion groups
- The successful launch of the “Under 60s' Club”

What could have been better

- Management of facilities and services at the venue fell short of expectations.
- The technical content of some presentations was too demanding for some.
- Some of the information in handouts supplied was not up-to-date.

Good Partnership between the Royal Bournemouth Hospital's CLL team and CLLSA

The Bournemouth Conference had a nice balance between local and national interest, as well as between CLL clinician and CLL patient input, thanks to the good partnership between our two organisations.

It was the Bournemouth CLL Clinical Team who approached the CLL Support Association with a request for us to hold a conference at Bournemouth. Their association with CLLSA goes back to its early days in 2004, when Professor Hamblin had helped one of our founding members, Chonette Taylor, his patient at Bournemouth, to set up the CLLSA.

Consultant Renata Walewska arranged with her colleagues in the Bournemouth Clinical Team to contribute half the day's programme, drawing on the expertise of three consultants to give talks on CLL as a disease, how CLL can affect the immune system and CLL treatments, as well as a PhD student's research into disease biology (Appendix 5.) Patients and care partners were very appreciative of all their presentations, as indicated by the 35 citations for them as one of the "most liked" aspects of the Conference. (Appendix 2.)

All our expert speakers agreed to be videoed. Their presentations, including slides, are uploaded on the CLLSA website, enabling not only those present to refresh their memories at leisure, but also those unable to attend the Conference to benefit from clinical talks tailored for CLL patients and their care partners.

We were delighted that Bournemouth and Poole sent out invitations to all their CLL patients inviting them to the Conference. This significantly swelled numbers by a further 45, resulting in 60 of the 92 patients and care partners in attendance coming from the Greater Bournemouth area. Some, registered through CLLSA publicity, had travelled from as far as St Austell, Canterbury, Ashbourne, Leicester and Essex to attend. Three charity and support group reps, local to Bournemouth, came for the day and staffed literature stands, in addition to the two national charities invited by the CLL Support Association. (Appendix 1).

The CLL Support Association used its national contacts and its expertise in conference organisation to ensure the strong clinical input was matched with active participation by CLL patients and care partners, specifically in the presentation of their CLL stories, through the discussion groups and in the launch of the "Under 60's Club", as described below.

The videoed short trustee presentation on the CLL Support Association's activities raised awareness of our national role to inform, support and empower CLL patients and care partners. Three videoed "CLL stories" – one on FCR treatment, one on "watch and wait" and one on Venetoclax and Rituximab treatment – gave the audience a good insight into how individual CLL experiences are, as well as how to manage the impact of living with CLL in a positive way. This aspect of the Conference was "most liked" by many. (Appendix 2).

Three attendees took up our invitation to become CLLSA Champions to spread the word on how CLLSA can support those affected by CLL. A measure of attendees' appreciation of the Conference was the very pleasing £1,517.50 raised in donations. This will contribute to our continuing policy of free membership of the CLLSA and free attendance at all our conferences nationally for members.

A well thought-through sequence of items on the programme

Experience has taught organising CLLSA trustees that the sequence of items on the programme is critical to holding members' attention. We know that members come for two things: to learn from leading CLL experts and to meet and share experiences with other patients and care partners. Our focus is on the patient and the care partner. For this reason, we place the "CLL stories" at the start of the day. It also ensures that our patient and care partner speakers do not suffer from a build-up of nerves.

We have also learned that a conference needs to finish on something which is a priority for our audience, otherwise up to a third of them depart early. By placing the expert talk on CLL treatments at the end of the day, we were able to keep our audience's interest. All at Bournemouth stayed an extra 15 minutes, beyond the official finish time, to listen to the full concluding presentation on CLL treatment and to ask questions.

Unusually high attendee satisfaction with the discussion groups

Normally, discussion groups are the most difficult aspect of CLLSA conferences to get right, as reflected in the satisfaction scores for conferences in 2018. At Bournemouth, the ranking was reversed, with discussion groups achieving the highest satisfaction. (Compare the right-hand column percentages of the table for conferences in 2018, with the scores given by "all respondents" at Bournemouth, Appendix 2.) Several factors may account for this high score at Bournemouth.

Care had been taken to ensure that the composition of groups reflected where people live. This enables people to meet others local to them. A significant majority, as indicated by a show of hands at the Conference, had never met another CLL patient before the Conference. Some exchanged contact details and hope to remain in contact or even form a local support group. One member was really pleased that he had sat with someone he knew from dog walking who he never knew had CLL; they can now get together for support.

All thirteen of the round-table discussion groups had a briefed facilitator. This ensures that discussion stays on track and all have an equal chance to participate. In four cases, facilitators were CLL consultants and a nurse from Bournemouth, thus enabling members to benefit from their expert knowledge. Two facilitators were experienced CLLSA trustees and two prospective trustees. Others came from our bank of members who have volunteered to facilitate.

The set topics for discussion were kept deliberately simple, to allow maximum opportunity for participants to shape the discussion and learn from each other. Record keeping was kept to a minimum. Details of the discussions can be read in Appendix 3. - Answers to questions, raised in discussion groups, which were not answered at the Conference, and in Appendix 4. – Tips volunteered by discussion groups for sharing with others.

Successful launch of the "Under 60s' Club"

CLL tends to be an older person's disease. Consequently, younger patients and their partners can feel even more isolated than other CLL patients and partners. In recognition of this, CLLSA decided to launch an "Under 60s' Club" for younger people affected by CLL. We had 20 expressions of interest nationally from our item in the CLLSA e-bulletin, the youngest being 29 years old. With the Bournemouth Conference being on a Saturday, it was possible for ten of these, some in full-time

work, to launch the Club in a specially convened discussion group, facilitated by prospective trustee, Norah Grant, herself in her 50's. She writes:

“There were ten rowdy youngsters around the table at the back of the room to launch the Under 60s Club in Bournemouth. Seven with CLL and three partners. One has had FCR, two are on Ibrutinib, four on “Watch and Wait”. The Bournemouth Conference was the first time most of them had met someone with CLL and they launched without hesitation to talk about travel insurance, low potassium, fatigue, worry, work and stress, whether CLL is a disability, and would that make them eligible for benefits? Also, can they all get the NHS exemption card? Most are working full time and that is the main reason they are different from the over 60 crowd; retirement is not always an option for relieving stress. Hearing about each other's experiences at Dimpleby Cancer Care, MacMillan and Maggie's were welcomed. Their concerns and questions were answered at the Conference, or soon after, and they were very pleased with the day. The Under 60s' Club continue to support each other in their WhatsApp and email groups.”

Three people mentioned the launch of the “Under 60s' Club” specifically as the aspect they “most liked” about the Conference.

Management of facilities and services at the venue fell short of expectations

Organising trustees and the CLLSA coordinator were disappointed with aspects of the service provided by the venue. This is reflected too in the feedback we received from attendees. Our venues are normally highly rated, and this has led returning conference attendees to have high expectations. Returners' satisfaction is noticeably lower than our first timers' in the rating given. (Appendix 2.)

Refreshments were poorly organised, with insufficient and poorly briefed staff, resulting in a long single queue, until we intervened to arrange two queues. Those at the end of the queue found some food had run out at lunch, limiting their choice.

Items ordered by us did not materialise: only one roving mic, no display boards for the table allocations... We improvised. Venue staff did not know how to work the wireless projector plug-in. Trustees and coordinator had to move the lectern and use a vga connector. We have provided feedback on all this to the venue.

These shortcomings notwithstanding, our attendees remained good-humoured. With a guarantee of better service another time, we would use the venue again.

Our failure to assist the two speakers to show their slides for the third “CLL story” was an omission by us organising trustees, for which we apologize. They are being uploaded on the CLLSA website, together with the video of their talk. One slide was retrieved and shown after the lunch break. It was a photo of the CLL patient's grandchildren being lifted up to see him smiling down from his hospital window at them – a memorable image.

The technical content of some presentations was too demanding for some

A significant minority of attendees, especially first-time conference attendees, found the technical content of the clinical presentations too difficult to follow. (Eighteen comments in total, 15 from first-timers. Appendix 2.)

It is difficult for presenters to pitch the content right for everyone in an interested, lay audience with differing levels of previous knowledge. We hope that the videos of presentations on our website will provide an opportunity to revisit the content. The jargon-buster provided to take away may also help.

To put these observations in a proper perspective, it should be remembered that there were many more positive comments than negative about the presentations – 35 citations as the “most liked” aspect of the Conference, 18 of them from first-timers. (Appendix 2.)

Some of the information in handouts supplied was not up-to-date

The representative from Lymphoma Action, formerly the Lymphoma Association, alerted us to the now one year out-of-date information on our hand-out on sources of information on CLL. This has given us an opportunity to review all the information on that sheet for the next CLLSA Conference in July at Newcastle.

Support services, personnel and CLL treatments are rapidly changing and expanding. Trustees have made a note to review all the printed information supplied at CLLSA conferences to ensure it fully reflects the current situation.

Report compiled by trustee, Olga Janssen.
6 June 2019

Composition of Participants at the Bournemouth Conference May 2019

Attendee Numbers:

Advance place bookings made:	111
Total in attendance on the day:	106
Cancellations post 15/5/19:	10)
No show on the day 18/5/19:	0) 10 (9% of 111)
Turned up on spec:	5
Waiting list, not accommodated:	0

Cancellation and no-show rates averaged 11% in 2016 and 2017, and rose to 14% in 2018.

With adequate notice we are able to reallocate relinquished places. We do our best not to turn anyone away.

Ratio of first-timers to returners

First time member attendees	44 (71%)
Returning member attendees	18 (29%)
(Unknown status members	<u>3</u>)
Total members	65*

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

For comparison, first timers were 51% overall in in 2017 (5 conferences) and 49.5% in 2018 (4 conferences).

Attendees by category

Trustees: BG; SS; OJ	3
Healthcare Professionals:	5
3 consultants, 1 research nurse, 1 PhD researcher:	
Charity Reps:	5
Leukaemia Care; Lymphoma Action; Wessex Cancer Trust;	
Bournemouth Leukaemia Fund; Bournemouth After Cancer	
Survivorship Fund	
CLLSA coordinator: ST	1
CLL patients (excluding trustees), 66% of 92	61
CLL partners (excluding trustees), 34% of 92:	<u>31</u>
Total:	106

Discussion Group composition:

CLL patients	62	(66%)
(Of whom on medical monitoring/ "watch and wait": 36 *)		
Partners	32	(34%)
Healthcare professionals (HCPs)	<u>4</u>	
Total	98	

** One group, with 7 patients, did not indicate how many were on medical monitoring.*

Discounting these, 36 of 55 or 65% of the patients were on medical monitoring/"watch and wait".

- 1. The 2 participating trustees are included in the 98. (One is "watch and wait", one a partner.)*
- 2. For comparison, in 2017 the % ratio of patients to partners was 68:32, in 2018 it was 66:34. and the % ratio of "ww" patients to other patients was 78:22 in 2017 and 62:38 in 2018.*

Analysis of returned feedback forms from participants

Satisfaction levels for the 5 aspects measured at Bournemouth, May 2019

	Not so good	Fair	All respondents		Excellent	Total respnd	%*	% 1 st time attend	% 2 nd plus attend	% 2018 all 4 conferences
			Average	Good						
Advert, register	1	2	4	25	33	65	87%	86%	86%	90%
Location, facilities	0	2	5	23	35	65	88%	89%	83%	92%
Event materials	0	0	4	26	35	65	90%	89%	91%	89%
Group discussions	0	0	1	24	39	64	92%	92%	92%	86%
Presentations	0	2	2	18	43	65	91%	89%	96%	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 65 completed feedback forms, from a total of 106 attendees, i.e. 61% return. Trustees (3), CLL coordinator (1) do not complete a feedback questionnaire. It is unusual for charity reps and speakers to complete a form. A return of 65 from the 92 patients and partners is 71%. We aim for a minimum return of 60% to be confident of findings.
3. Of the 65 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 62 returns, 44 were from first-time conference attendees, i.e. 71%.

Key findings

1. Unusually, group discussions scored highest of the five aspects measured. Normally it scores lowest. This is a difficult aspect of conferences to get right, because there are so many variables beyond organisers’ control.
2. First timers found the presentations more challenging than returning attendees.
3. Returning CLL Support Association conference attendees have higher expectations of the venue than first timers.

Analysis of returned feedback forms from participants Answers to open-ended questions at Bournemouth, May 2019

Most Liked

63 responses, 2 no response. 42 first timers; 18 returners; 3 not known.
Some gave more than one aspect as “best liked”.

1. Meeting others with CLL, group discussions, patient and carer stories

38 citations (25 first timers, 12 returners and 1 unknown)

“The opportunity to meet others with CLL – this was extremely valuable”

“Not alone! Patient and carer stories.”

“The community impact.”

“Facilitated small group discussions.”

“Good mixture of patients on table, some new, some long surviving.”

“Finding out other CLL patient symptoms, sharing experiences.”

“Great opportunity for networking and discussion.”

“Meeting other patients for the first time under 60.”

“Group involvement.” Group discussions.”

2. The presentations

35 citations (18 first-timers; 15 returners; 2 not known)

“A good mix of speakers and all talks very informative.”

“The presentations with animations. I feel the patient can understand better with pictures and diagrams.”

“The basic explanation of CLL and treatment. The genetic talk was excellent.”

“Talk about immunotherapy.”

“The expertise of speakers.”

“Good spread of basic information of the condition.”

“Fantastic presentations.”

“The talks make a complex subject easy to understand.”

“Very clear and current.”

3. Friendly, supportive and positive ambience

“Very friendly.”

“Positive view point.”

“A real help with problems.”

“Like-minded fellow participants.”

“General support.”

“Good, even networking at break.”

4. Very informative

“A wealth of diverse information.”

“A most informative day.”

“Knowledgeable forum for receiving information and answering questions.”

“Answers to specific questions.”

5. Other compliments

"Well organized."

"Lovely lunch."

"That it happened at Bournemouth."

"Good to see consultants out of clinic all day."

Least liked

49 responses. 8 of these responded: "nothing" or "n/a". And one wrote: "I was pleasantly surprised how helpful I found the day – no negatives."

1. Presentations were demanding in technical content

18 commented on this: 15 first timers and 3 returners

"I found a lot of it too technical and difficult to digest/understand."

"Too many big words!"

"A lot of it went over my head."

"Complex, medical science information."

2. Catering: lunch and tea break

9 people mentioned this

"Catering facilities for lunch and no coffee/tea."

"The queue for lunch."

"Lunch was not very good."

"Having to make tea with a bag. Lunch ran out and cleared away before we finished."

3. Other negatives

5 mentioned specific presentations. Other observations were:

"Too many slides" (2 comments)

"Lettering on slides too small."

"Whole day a lot to swallow!"

"Too long." (2 comments)

"Chairs"

"Hard to hear others at the table."

Answers to questions, which were unanswered at Bournemouth

Please find below answers from CLLSA trustees.

1. How can we make Ibrutinib a first line option for NHS?

Ibrutinib can be prescribed as first line treatment for patients in certain circumstances, for example, those with certain genetic markers, notably 17p deletion together with being unmutated. However, fit patients without these markers will usually be prescribed FCR and may well get good and lasting results.

CLLSA will continue to campaign for all new drugs to be available as frontline treatments, and we believe this will eventually happen when enough evidence has been gathered.

2. Can lower back pain be caused by cells being made abnormal?

It really depends on the nature of the back pain. CLL can cause enlargement of the spleen, which may result in pain in the abdomen area and possibly the back. In addition, fatigue, which is often associated with CLL, can lead to muscle aches. A persistent back pain should always be referred to your consultant as soon as possible to rule out other causes.

3. Why do the intervals between being seen in clinic keep on changing: 3-monthly; 6-monthly; yearly?

On diagnosis, your consultant may wish to establish a 'base line' for your CLL and this requires several blood tests, usually spread over a period of time, often at three-monthly intervals. If it becomes clear that the CLL is at that point stable, blood tests can be spaced out further, just to keep an eye on what is happening. In general, the further apart your tests, the more indolent is the disease, and the further away from treatment you are.

4. Can I change anything in my lifestyle that will slow the progression of my CLL?

The short answer is 'no', as there is no evidence to suggest that a change in lifestyle can affect the progress of CLL. However, many patients report feeling better for changing dietary habits, for example eating more fruit and vegetable; taking more exercise, and losing weight if overweight. These are very standard elements for a healthy lifestyle, and the fitter you are the more likely you are to be able to cope with treatment if it is necessary. Caution should be used in taking any dietary supplements, as some can have an adverse effect, and can interfere with treatment. Always refer any changes to your consultant.

5. How do we push for access to a clinical nurse specialist (CNS)?

All research shows that CNS's make a huge difference to a positive patient experience. Unfortunately, there is a national shortage of CNS's. Where a hospital does have a CNS, the work load is heavy. Inevitably, CNS's have to prioritise those cases where their support is most needed. However, if you would like to see a CNS, do ask at the clinic you attend if this can be arranged for you.

6. Privigen is given every 28 days in hospital by a lengthy intravenous dose. Is there any alternative, for instance develop a patch which can be self-applied at home? This would help the patient and save hospital costs.

Privigen is the brand name for IVIG, a preparation of highly purified and concentrated immunoglobulin G (IgG) antibodies. It has to be administered intravenously, because of the volume required, and because it must go directly into the bloodstream. It is possible to self-administer IVIG at home after a course of training, and many patients do this successfully.

7. Why are there not more speakers covering the psychological aspect of the disease?

The CLL Support Association recognises that this is an important issue for both patients and their care partners. At our March 2019 Cambridge Conference, we included three speakers on coping with the psychological impact of living with CLL. Our speakers did not want to be videoed, but we hope to draft some tips for members on managing the psychological aspects. It's work in progress.

CLLSA has been working with Leukaemia Care and CLL specialist haematologists to add a section on the psychological aspects of Living with CLL in the updated NHS Clinical Guidelines for the Management of CLL.

8. Carers need support and appreciation!

We agree! It can be more difficult to be a carer than a patient. Our London Conference in November 2017 focussed on this and you can read the advice given in the Conference Report on the CLLSA website. We also try to include a carer's story in conferences.

9. Why is it more common for men to get CLL than women?

It is not known.

10. When will "dead" vaccine for shingles be available?

Unfortunately, there is no date for the introduction of Shindrex, the non-live shingles vaccine, although it is available privately at a very small number of pharmacies in the UK. It is important to remember that tests are still being done to assess the safety and effectiveness of Shingrex in CLL patients. We are monitoring this and as soon as approval in the UK is announced, we will let all our members know.

11. Is CLL considered a disability? Are you entitled to benefits because of it?

Our understanding is that CLL is classed, rightly, as cancer, and is therefore also classed as a disability. There is a set procedure to follow which includes confirmation by a doctor of the CLL, but also a judgement by social services as to the extent that CLL is affecting the patient.

The problem with CLL is that it varies from patient to patient, and often from day to day. Our advice is for the patient to contact MacMillan, who are very good at this sort of thing, and will be able to give help and guidance.

12. Do you have advice on travel insurance? It doubles the cost of a holiday abroad for me and my husband and we do love our overseas holidays.

The CLL Support Association is including a section on travel insurance in the information booklet for members, due out later in 2019. In the meantime, here are some possible companies:

Ten insurers who are prepared to go the extra mile to help travellers with cancer or other serious pre-existing medical conditions:

1. Avanti Travel Insurance
Specialise in pre-existing conditions and over-50s travel.
avantitravelinsurance.co.uk
2. All Clear Insurance
Has covered more than 500,000 people with medical conditions. Any condition. Any age. Any destination. allcleartravel.co.uk
3. Insurancewith
Aims to provide affordable policies to travellers with a serious medical condition.
insurancewith.com
4. InsureCancer
Specialises in providing cover for travellers with active, metastatic, relapsed or terminal cancer. insurecancer.com
5. Freedom Insurance
One of the first UK insurers to develop specialist travel insurance for people with pre-existing conditions. freedominsure.co.uk
6. JD Travel Insurance
Offers good value, tailor-made cover for travellers with pre-existing conditions.
jdtravelinsurance.co.uk
7. PJ Hayman
No upper age limit on single or annual multi-trip cover for most conditions and disabilities. freespirittravelinsurance.com
8. Pulse Insurance
Specialise in difficult and declined cases for individuals and groups.
pulse-insurance.co.uk
9. Staysure
Medical travel insurance available to over 50s. staysure.co.uk
10. World First
General insurer offering a range of options including medical travel insurance.
world-first.co.uk

Bournemouth CLLSA conference 18 May 2019

Tips for sharing with others

Our 13 discussion groups put forward the following tips for coping with CLL. They are presented below in common themes. We hope you find a tip that you would like to adopt for yourself, but please do check with your CLL consultant or nurse specialist first regarding tests, treatments and precautionary measures.

Two heads are better than one. And keep notes.

Get a buddy!

Hunt in pairs! Two are much more efficient!

Attend clinic appointments with a care partner or friend, to keep track of information you might have missed and take notes.

Keep a diary: both the patient and the care partner.

Look after yourself and enjoy life.

Eat well, have a good holiday, keep positive.

Just get on with life.

Have a hobby.

Try out the University of the Third Age (U3A).

Recognise the stage of your CLL and work to manage it as best you can.

Exercise is beneficial, both physically and mentally.

Exercise.

Exercise after chemotherapy.

Walking is good for you, both physically and mentally.

Stay calm.

Don't panic when you hear the word "leukaemia".

Try not to worry! Forget about the diagnosis!

Use meditation.

Protect yourself from infection and from injury.

Carry anti-bacterial gel/spray with you, use it on your hands and when opening doors to prevent infection.

Be careful about risk of infection with food, e.g. salads not washed properly, food left out on display.

Take care with food preparation.

Avoid community swimming pools and spas.

Have upfront conversations with family and friends about your vulnerability to infections.

Use gloves and sleeves for tasks with risk of minor injury.

Dietary advice.

Get good dietary information.

Find out about a neutropenic diet.

Up your potassium.

Decide what information you want and how much. Then go for it!

Know the level of information you want. Some people need all their results; others are happy with just an instruction i.e. “watch and wait”.

Empower the patient to seek as much knowledge as they wish to have. Recognise everyone is different. Some CLLers may prefer not to know too much.

You can't ask too many questions.

Seek help and advice from the professionals.

Don't order genomic screen privately, e.g. on a genealogical website.

Get a Clinical Nurse Specialist (CNS) contact number for queries or concerns, or a research nurse's if a trial patient.

Get a referral to a specialist consultant. (Our forthcoming member booklet offers advice.)

Ask for the FISH test and test for your mutational status.

A couple of practical tips

Use a heat pad to help dilate veins, if necessary, before blood tests.

Buy a good thermometer.

And a tip for the CLL Support Association

Encourage people to make online donations to the CLL Support Association and gift aid.

We are delighted to announce that we received £1,517.50 in donations at Bournemouth.

Thank you, everyone!

Three volunteers came forward to become profile-raising champions for the CLL Support Association. This brings our total nationally to 102. Excellent!

CLL Support Association Conference – Bournemouth

Saturday 18th May 2019

Bournemouth Village Hotel, Deansleigh Road, Bournemouth BH7 7DZ

See website for details: www.village-hotels.co.uk/hotels/bournemouth

Programme

10.00 a.m.	Arrival, refreshments, meet table companions	
10.30 a.m.	Welcome and Introduction by a CLLSA trustee	Olga Janssen
10.40 a.m.	CLL Stories Three patients and a partner tell their stories. Every experience is different.	Matt Gibson Norah Grant Kevin and Sue Powell
11.15 a.m.	CLL, an Introduction Ram Jayaprakash is a consultant haematologist at Poole with a particular interest in CLL, including the FLAIR trial.	Ram Jayaprakash
12.00 noon	Epigenetic Research in CLL Lara Makewita is a PhD student at Southampton University. Her talk looks into CLL disease biology.	Lara Makewita
2.30 p.m.	Lunch	
1.30 p.m.	CLL Support Association News , given by a trustee Achievements, developments and volunteers.	Brian Gardom
1.45 p.m.	Facilitated Small Group Discussions Who's who at your table; getting answers to your questions from table companions and sharing tips for coping with CLL.	
2.30 p.m.	Tea	
2.45 p.m.	CLL Effects on the Immune System – a Double-edged Sword Haematology consultant Helen McCarthy runs a dedicated CLL clinic at Bournemouth and leads the clinical research team with a large trials portfolio.	Helen McCarthy
3.15 p.m.	CLL Treatment: the Old, the New and the Available Renata Walewska, haematology consultant, Bournemouth, is an active member of the UK CLL Forum. She contributed to the recently updated national British Society for Haematology (BSH) clinical guidelines for CLL. She is a clinical advisor to the Evidence Review Group for NICE appraisals.	Renata Walewska
3.55 p.m.	Conference closed by a CLLSA trustee	Olga Janssen
4.00 p.m.	Depart	

