Report on the CLLSA London Conference, 8 November 2018

"Best was the member story, but everything was excellent, Q&A excellent."

"Best part was meeting and talking to fellow CLL patients."

"Best was whole thing!"

Report Introduction

Above is a sample of the highlights from the 86 members who attended the fourth of this year's four scheduled conferences. It was held at the ETC Venue, 1 Drummond Gate Pimlico, London. Key speakers were:

1. Dr Dima El-Sharkawi, Consultant Haematologist at the Royal Marsden Hospital.
2. Dr Parag Jasani, Consultant Haematologist at the Royal Free London and University College London Hospital
3. Members Stories – Susan Cracknell and Elizabeth Pearson.

The conference included a CLLSA update and member workshop. This involved what members need from the CLLSA and the launch of the new 'CLLSA champions' roles.

The report is based on attendee feedback and is prepared for the speakers, CLLSA trustees, conference facilitators and volunteers, attendees, LeukaemiaCare and Bloodwise representatives and anyone else interested in CLLSA Conferences.

Videos and slides of presentations have been mounted on the CLLSA website.

The report contains:

- What worked well, based on feedback
- What could have been better, based on feedback
- Appendix 1. Composition of attendees
- Appendix 2. Analysis of feedback form returns
- Appendix 3. CLLSA Profile Raising and other Champion Roles
- Appendix 4. Analysis of group discussions' feedback on members' issues, their CLL clinics and what they want from the CLL Support Association.
- Appendix 5. Dr Dima El-Shakarwi's responses to outstanding questions
- Appendix 6. Conference Programme

What worked well

- Guest speaker content and opportunity for Q & A
- Event organisation, timing and content
- Meeting fellow members

What could have been better

- Simplifying some of the expert content and table paperwork
- Fewer slides so less rushed at times
- More table room and higher projection of slides

Speaker Commentary

51 of 56 members' feedback on the presentations rated them as excellent or good. All written feedback is listed is appendix 2 with illustrative quotes included in the commentary below.

We opened the conference with a traditional members' CLL story. Elizabeth Pearson and Susan Cracknell, members from the Isle of Wight, gave a unique and personal account of their CLL experiences. Friends for 35 years, Elizabeth's husband Lester had CLL and sadly died in January 2018. Lizzie shared the journey, errors and failings in local treatment. Susan, a CLL patient diagnosed in 2014, also shared some local treatment issues resulting in her decision to move to Royal Marsden where she feels 'safe'. As a result of the local experiences in particular they are helping educate and support their local GPs and hospital re CLL and look to form an island CLL support group. They shared helpful tips culminating in playing Louis Armstrong song 'A wonderful world' emphasizing the advice to be positive and enjoy life.

Feedback included: *'Sue and Liz were fantastic and the most useful part to me'. 'Best was the member stories, but everything was excellent. Q & A excellent'. 'Set the scene well, giving an insight in the gulf in patient experience in a small community and in the metropolis.'*

The keynote speaker at this Conference was Dr Dima El-Sharkawi. Dima was recommended by Professor Stephen Devereux, the original speaker who was retiring and recommended her as his replacement. Dr El-Sharkawi is a Consultant Haematologist at the Royal Marsden Hospital with a special interest in CLL, lymphoid malignancies and haematology malignant diagnostics. Her clinical research interests focus on the translation of scientific advances into clinical practice, and she is an investigator on a number of clinical trials. Her presentation focused on the management of CLL in the past, today and potentially in the future.

She explained where CLL come from, where it stands in the cancer rankings, how it is diagnosed and how the prognostic tests and markers indicate likely survival ratings. Dima then moved on to the rationale behind Watch and Wait, the evidence supporting this strategy, how health, fitness, stress and other factors can prolong or shorten the time until treatment is required. Dima then moved on to outline when treatment should start, options and goals of treatment, plus considerations that influence treatment options. FCR is still the gold standard though new drugs and treatments are being developed. Dima covered how the new drugs impact on the CLL pathways, current research and trial results particularly covering Ibrutinib and Venetoclax. Dima briefly

covered newer therapies such as Immunotherapy, Idelasib and Car-T therapy. Dima answered many questions from attendees, questions supplied that could not be answered in the time available, she kindly answered later and are listed in appendix 3.

Feedback included: *'Expert talks were best and being able to talk to Dima about specifics', 'Best part was the presentation by Dr Dima El-Sharkawi'. 'Demonstrated the complexity of the disease, treatments available. Good on both the extent of expert knowledge and its limitations.'*

An update on CLLSA activity was presented by David Innes (CLLSA Chair). David provided an update on UK CLL patient numbers, acknowledging they differed from Dima's numbers. He explained how the Blood Cancer Alliance of twelve fellow blood related charities gave us more influence, illustrated by meetings with senior NHS England leaders to influence future cancer strategy and to ensure Blood cancers were seen as important as the more common 'hard' cancers. The Chairman also shared recent CLLSA achievements and progress including access to Ibrutinib treatment. David shared the result of the recent CLLSA survey which is now influencing the refresh of the website and the drive for members to champion CLLSA in their encounters with healthcare professionals. Other initiatives are: new information packs, new look email-based news bulletin to members and the increase to 6 national member conference in 2019. David reminded all of the services currently on offer and the plan to increase fund raising to help finance the extra activity and member benefits. Help from members to raise funds and assist with donations was greatly appreciated.

Feedback included: *'Clear delivery on CLLSA's role and developments, well pitched.'*

We then held our members 'workshop' an opportunity for members to volunteer to help with key CLLSA activity and to consult members on their CLL experience and the role of the CLL Support Association. This was led by Roger Huxley and Olga Janssen and facilitated by trustees and volunteer members attending.

Our Second Expert Speaker was Dr Parag Jasani. Dr Jasani is a Consultant Haematologist at the Royal Free London and University College London Hospitals (UCLH) NHS trusts. His special interest is CLL and Lymphoma. He is a member of CLL clinic at UCLH. He is also a principal investigator for various clinical trials for CLL. Parag had 40 minutes and his topic was 'Cure in CLL'? Parag opened by asking: do people want a cure? What if the disease can be managed for your entire life? This led him into explaining Minimal Residual Disease (MRD) negativity, how it is measured, why it is important – because the deeper the remission, the longer the survival rate generally. He then moved to the treatment regimes over the past 50 years and what percentage resulted in MRD or equivalent. Parag then focused on latest clinical trials, new drugs and combinations both in the UK and the USA. These showed improved MRD results. Parag ended on Car-T therapy. BiTE (Bivalent antibody i.e. Blinatumumab) and Allogenic transplant but emphasised cost is an issue. Parag presented all his slides with time for a good Q&A session. In the Q&A session, Dima, who stayed all day to learn from and interact with our members, challenged Parag over the as yet unknown long term impact of which Parag acknowledged.

Feedback included: *'Dr Jasani, his slides were easy to understand'. 'Both speakers were excellent!' .'Good use of audience participation to explore cure concept.' 'Clear summation of MRD, use of new drugs earlier in treatment and costs challenge.'*

Nick York from CLLSA's sister charity LeukaemiaCare and Dawn Stone Bloodwise were present providing information and literature to members.

Video Clips to welcome attendees at the start of the conference

A series of video clips of CLL patients as well as a short talk from Professor Fegan of Cardiff University were shown while people arrived and awaited the start of the conference. This was well received as it helped provoke conversation and interest for early arrivals.

Feedback included: *'Attendees were tickled to see themselves on screen, good to have clips as they were a conversation trigger for early arrivals'*

Meeting fellow members

Attendee were allocated table groups based on their post code to try and encourage local contacts where possible. In the breakout groups members helped contribute to the development of the CLLSA and its work to raise its profile.

Feedback included: *'Best was the table talks', 'best part was meeting and talking to fellow CLL patients.'*

Improvements identified in previous conferences resulted in all present attending the same seamless member workshop session for the London conference. Participation was based on existing table groups with facilitators who were with them from the start. This improved the speed to engagement with tasks, quantity and quality of discussion. (See appendix 4 for details.)

Organisation and timing

The conference agenda was busy but reducing to two expert speakers and streamlining the member session gave a better balance, allowed more time for Q and A and for table discussions.

Feedback included: *'Unobtrusive time management and running order ensured the event ran smoothly.' Sue and Elizabeth were a good opening warm up double act! Parag as the final presentation resulted in fewer early leavers and ensured the day ended on a high of information.'*

Table seating and venue

The venue facilities and site support were very good. Refreshments and food were varied and easily available though the tea queue was long at times. There was also signs to show which choices were safe for those suffering from neutropenia. Some felt the dining seating was a little cramped. The conference room itself is shallow and wide with kidney shape tables. While this ensured the audience was close to the speakers and screens, it constrained flexibility in seating. For the member workshop it was difficult for facilitators and attendees to move seats to face each other in a circle. The three presentation screens were low so some attendees in the third row of tables sometimes found it difficult to see the bottom of the slides displayed.

Feedback included: *'Seating in hall and lunch were cramped making circulation and networking difficult'. 'Just 5 on a table made well-informed discussions difficult due to the limited range of experience.'*

86 out of 100 attendees booked turned up. 9 cancelled on the day either by email or via partner who attended, 27 attendees pledged or contributed a total of £1,210 in donations, a conference record.

Marc Auckland
18 November 2018

We received very high satisfaction scores for all five aspects measured: advertising and registration; location and facilities; event materials; group discussions; presentations. (Appendix 2)

Composition of Participants at London Conference Nov 2018

Attendees:

Total places booked	100
Total in attendance	86
Cancellations before the day	38
Cancellations on the day	9
and no show on 08/11/18	5
Waiting list, not accommodated	15

Late cancellation/no show 14/100 = 14%
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	21 (35%)
Returning member attendees	37 (62%)
(Unknown status members	(2) (3%)
Total members	60*

**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; FM; DI; OJ; RH; GW	6
Healthcare Professionals:	
Clinicians: DE; PJ	2
Charity Reps:	
Leukaemia CARE:	
Bloodwise	2

Analysis of returned feedback forms from participants

Satisfaction levels for each aspect measured at London, 8 November 2018

	All respondents							% 1st time attend	% 2nd plus attend	% 2017 all 5 con-ferences
	Not so good	Fair	Aver-age	Good	Excell-ent	Total respnd	%*			
Advert, register	0	1	2	18	38	59	92%	88%	94%	90%
Location, facilities	0	0	1	14	45	60	95%	93%	96%	92%
Event materials	0	0	1	24	35	60	91%	91%	91%	92%
Group discussions	0	1	3	25	25	54	87%	87%	88%	88%
Presentations	0	0	5	15	36	56	91%	86%	94%	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 60 completed feedback forms, from a total of 86 attendees i.e. 70% return. We aim for a minimum return of 60% to be confident of findings. Trustees, (6) CLL coordinator (1) and visiting speakers (2) do not complete a feedback questionnaire. Charity reps (2) sometimes do.

3. Of the 60 completed feedback forms, 2 did not indicate whether they were first time attendees. Of the remaining 58 returns, 21 were from first-time conference attendees, i.e. 36% This compares with Bristol (July 2018) 69% Birmingham (May 2018) 51% 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 - **Feedback Comments (black from first time attendees, purple for repeat conference attendees.)**

59 of respondents commented, often giving more than one factor as best. There was hardly any difference between first timer attendees' and returners' positive comments. As at other CLLSA conferences, clinical presentations, meeting other CLLers and sharing experiences were the aspects most liked.

Presentations

36 respondents identified the speakers as the best aspect of the conference, four also mentioning the linked Q & A sessions as best.

Best was Dimas talk.
Best was presentation by Dr Dima El-Sharkawi.
Best was the member story, but everything was excellent, Q&A excellent.
Presentations were very effective.
Expert talks and being able to talk to one to one with Dima about specifics.
Best was Q&A after talks.
Best was information and presentation by Dima.
Two speakers were excellent.
Best was the quality of the main presentations.
Best was members CLL presentation and meeting people like me!

Expert Presentations best.
Sue and Liz, brilliant information, useful tips.
Dima – very good, clear and precise.
Best was presentation by Dr Dima – full of information and insights, it could have been longer as it became rushed.
Best lots of highly qualified information and meeting likeminded people.
Best was presentations by experts and patients. Plus, meeting other CLL patients
Best was information and uplifting patient/member stories
Best was combination of member stories and Dr presentations
Dr Janani's slides were easy to understand.
Everything was so well organised, speakers especially Parag was brilliant.
Best was Sue and Elizabeth
Good Location, moving and humanising first presentation.
Sue and Liz were fantastic and the most useful bit to me.
Good to speak to the experts and ask some personal questions as well as listen to them.

Meeting other CLLers and member workshop

Best was meeting people with CLL for the first time.
Best was sharing stories with other CLL patients and quality of the speakers, all very worthwhile
Practical steps, talking to other CLL patients.
It was good to have a chance to speak to other CLL patients and understand their experience and knowledge
Being made aware of the existence of friendly knowledgeable support there when I need it.
Discussions with other CLL patients.
Meeting other delegates, sharing information, opportunity to ask questions. Exchange of ideas.
Best was small group discussions – more time would be good to exchange info and experience.
Talks and group talks were best.
Meeting others with CLL was best
It was very informative and it was nice to meet with others and share experiences and our journey with CLL.
Meeting other people
Meeting others in a similar situation was best part.
Being able to chat with other patients on watch and wait.
Best was experts and meeting other CLL patients
Best group discussions.
Best small groups on tables so you could talk to each other.
Best was face to face contact with like people
Best, the coming together of similar people.
Best was opportunity to meet and exchange views/opinions etc with fellow CLLers.

Conference facilities and Organisation

The information given by the speakers and hearing about the CLLSA
Well organised, quality of speakers, keeping to time.
Best was morning medical presentation, lunch and catering
The jargon buster was brilliant to understand the talks.
Nothing was poor, would have attended earlier if in Norfolk (Cost)
Everyone was approachable.
Best was talks by specialists, meeting others in the CLL community (and lunch)
Best was ability to network, hear about other people's experiences and the expert talks.
Good speakers and meeting other CLLers.
Best was expert presentations, exchange of information with others and excellent venue.
Best was networking opportunities. Information, updates and HOPE!
Best was quality of presentations, location and facilities.
Excellent venue, not as beautiful as Bart's but warmer and better acoustics.

There was nothing bad!
Best was networking, patient stories and treatment options.
Best was opportunity to meet other with CLL, expert speakers, update on CLL management and update information.
No worst, excellent day!
Best was talking to others.
Best was exchange of information, talking to others, the patient story and Dimas presentation.
Best was whole thing!
Best was being part of something.
I enjoyed it all!
Good venue.
Well organised and well thought out.
Champions map display

Least liked

22 of the 60 respondents left this question blank or simply wrote *"nothing" or "all good!"*

Presentations

The information provided was great but some was too in depth.
Key speaker slides were too technical, hard to read. Need simplified headlines only.
The first presentation was very informative but too much technical detail/graphs/pictures.
The length of the first medical presentation, the number of and complexity of the slides
Can we have less technical details and more support to 'live well', QOL and mental health.
Both clinical speakers very heavy, lots of info thrown at us, hard to take in. less science more case studies, real life examples.
First speaker Dima excellent but spoke very fast, felt bombarded with medical information - would have liked a break between findings.
A lot of the medical info went straight over my head.
Presentations were rather over long and detailed.
Dr Dima too technical, too much info.
Did not value stats on progress.
Worst was talks and feedback.
Complexity of technical lecture.
Dr Dima, brilliant academic, some of her talk above my head but she was very informative.
CLL members story – not so much a 'half full' glass as a full and over flowing. CLL strips away the dross of life and help you concentrate on what is important.
Slides were too many and too difficult to read.
Too much technical detail.
Presentations may have been too technical; a first timer may have had comprehension issues!
Dr Dima is clearly a first-rate specialist, I thought her presentation was too technical and she needed to be more time conscious.
Some overlap between two speakers, the second presentation should be about management of CLL including W & W and management of co-morbidities.
Stats and graphs with details to hard. Know it is realistic but left me negative.
Sad first presentation, very emotional. Also, too many graphs on first professional presentation.
Too much info and graphs.
Would have like more information in layman's terms.
Worst was clarity of slides.
Worst was length pf Dr presentation, split workshops on topic (W&W/1st Line/2nd Line)
Some medical slides difficult to see and understand. 1.5 hours too long to concentrate.
Speakers pointer did not show up on all three screens.
Lots of slides that were difficult to read from the floor.

Meeting other CLLers and member workshop

Group discussions frustrating as other members talking over you.
Champions sound good but did not get the vision of how it would work.
Too much discussion about CLLSA – would like more medical input, perhaps opportunity to have private chats with the doctors.
Update on CLLSA, developments – staccato delivery, and way, for me, meandering and lacked focus. Keep to the point.
Paperwork needs streamlining
It might be helpful to prepare folder with all the documents together, I found a lot of loose papers.

Conference facilities and Organisation

Long coffee queue in afternoon.
Long tea queue
Speed of service lunch, seating availability at lunch.
Worst was organisation of seating by clinic where possible to seat groups.
Slight overcrowding table layout.

Profile Raising Role Champions Breakout Group.

After lunch, Roger Huxley explained the CLLSA board were keen to build on last year's survey where members volunteered to help their Association in various ways. The roles were defined below and members would be called champions in these roles.

Role Definition

A member who volunteers in any CLLSA approved project or ongoing activity which involves spending time unpaid that benefits the Association and its members. Champions will select and support one or more of the Specific Support Areas listed below dependent on personal choice and trustees' selection based on the individuals' skills.

Specific Support Areas

CLLSA Profile Raising Champions	Visiting Local GP Surgeries, CLL Clinics, CNS and Specialist teams to promote awareness, supply welcome packs for new, existing patients. Local first point of contact encouraging local CLL patients to join the CLLSA.
Fund Raising Champions	Special events, personal and team challenges, sponsoring. Gift Aid, Donations
Event and Regional Forum Support Champions	Helping set up and facilitate conferences. Telling your CLL story. Note taking. Support set up and run local support groups
Lobbying and Media Support Champions	Contacting, briefing, lobby support of MPs. PR with local media to raise awareness. Supporting Newsletter
Help line Champions	Staffing the line, collating topics of calls for common Q and A section of Website.
Digital Champions	Promoting CLLSA on social media. Managing blogs, Facebook page, on line Forum adjudication, Group emails

Role requirements

Essential	Desirable
• Good Communication Skills • Good Organisational skills • Self-Motivated • Confident with people • Reliable	• Previous experience in the specific areas.

After lunch and the CLLSA Chair's update on the CLLSA, breakout sessions for Raising our Profile Champions were run. Trustees and volunteers facilitated. There were a range of responses to involvement with many showing real enthusiasm and offering to put on a roadshow at clinics! 32 attendees volunteered to be profile raising champions.

Ideas Coming from Champions Discussion Groups

Idea	**Discussion Points (Pros, Cons etc)**
Visit own GP – give leaflets	Benefits / issues shown on our leaflets
Visit other GPs in the area – with leaflets	"
Take leaflets to Clinic	"
Become a Buddy	Offer appropriate support e.g. telephone, or email – perhaps face to face where possible. Benefits both Patient and Buddy – more awareness of CLLSA and CLL by appropriate training and support
Develop the P.R. role	Benefits to both clinical staff and members alike
Set up local support groups	• Someone to co-ordinate the group, benefits of face to face support, • giving advice on such matters as vaccinations, vitamin supplements etc.
Need to engage more with Social Media, incl. improve website	• Improve CLLSA website, • A jargon-busting guide publication, • Regional promotion/news via web pages, Full and complete guidance in a "realistic" format on web and leaflets to reflect living a life on W & W, • target senior health professionals (from Dr El-Sharkawi) • The Captcha on the website is difficult for people with visual impairment
Reliable sources of information and knowledge	• Via website, Conferences, Publications. • Belief that information is the best available and exchange information with other organisations. • Nominate local sources of support (e.g. someone to approach) • Wider access to world-class specialists – e.g. through larger Conference capacity • Through knowledge patients will know what questions to ask the clinicians
Re-balance the CLLSA funding profile	• Gradual move away from pharma-funding • Recruit trustees with fund-raising work experience
Using digital signs in GP surgeries to promote CLLSA	Patients can view the information on CLLSA while waiting for appointments
"Give as you Live" funding for CLLSA	Additional fundraising

CLLSA London Conference 8 November 2018

Discussion Groups' Activity
"Me, my clinic and the CLL Support Association"

Our aims for the discussion

We had three aims for this discussion group activity.

- **"Me"** - To give members an opportunity to share any concerns with others, in a small group, and benefit from the experience and tips of fellow members.
- **"My clinic"** - To learn about good practice in CLL clinics attended by members, so that this could be shared, and possibly adopted, elsewhere.
- **"The CLL Support Association"** - To find out what members most valued about CLLSA; what difficulties, if any, they had encountered as CLLSA members and what CLLSA might do to address those difficulties.

Composition of Groups

Eighty people participated in our small group discussion activity. We had 14 groups, ranging from 4 to 9 participants per group. Composition of the groups was:

CLL patients:	49	61%*
Partners:	27	34%
Healthcare professionals:	4	5%
*Of whom on "watch and wait"	33	67%

The ratio of patients to partners was typical of the last 8 CLLSA conferences, which have averaged 65% patients to 32% partners, with 3% healthcare professionals. The percentage of patients on "watch and wait" at CLLSA conferences fluctuates. It has averaged 50% of all patients in attendance, with a low of 29% and a high of 79%.
This London 2018 incidence was at the higher end of the spectrum at 67%.

1. "Me":
Members' issues, where advice was requested from others in their group

We have grouped requests thematically in the list below. Where more than one group raised exactly the same issue, this is indicated in brackets.

This section of the discussions revealed the wide range of members' concerns and their need for more information. It's the CLL Support Association's role to help with information and support.

We will be incorporating much of the information requested below in our new member booklet, due for publication in June 2019. In the meantime, we recommend the excellent resources available on the CLLSA website and the publications of our sister charities Leukaemia Care, Bloodwise and Macmillan.

Other CLLSA projects have anticipated and are responding to some of the issues raised.

For example, we are working with Leukaemia Care and CLL consultants to establish agreed guidelines for good practice in communicating a CLL diagnosis to patients and providing them with information on tests.

Another initiative this year was to partner Leukaemia Care on a pilot buddy scheme for CLL patients, which we hope will be funded to continue in 2019.

Some of the issues raised below lend themselves to a more in-depth coverage at future CLLSA conferences, either through an expert presentation or by a public debate.

Issues around "watch and wait"

- When does "watch and wait" become an issue if at all?
- Lack of support on "watch and wait"
- No interest in "watch and wait" at clinic
- Wondering and worrying whether treatment will ever be needed if on "w and w"
- Launched into "w&w" by GP on diagnosis, without adequate guidance and support.
- Pain management on "watch and wait".

Advice on diagnosis, testing and treatment options

- Lack of information at diagnosis
- What to expect at diagnosis and why is diagnosis so early?
- Vaccinations – lack of knowledge
- When should diagnostic marker testing be done?
- Trials, whether to go on a trial
- Side effects of idelalisib
- Print-off of blood counts
- Having information available on prognostic markers.
- Layman's interpretation of results of cytopenia

Getting the best possible care

- Access to a CLL expert / Transfer from clinic where diagnosed to a centre of excellence/ what to do if my hospital does not have any CLL expertise? (3)
- Designated clinic rather than general hospital clinic
- Does quality of care change by postcode?
- More bad experience than good at local CLL clinic (3)

Support needs

- Lack of / access to/ contact with CNS (3)
- Contact with a CLL patient buddy
- Use of carer in relation to the patient. Who looks after the carer?
- A gold standard of minimum standards to expect in information given at time of diagnosis and clear signposting to CNS and support services
- Should you disclose you have CLL?

Management of the physical, emotional and psychological impact of CLL

- Fatigue. Doctors don't place enough emphasis on fatigue (3)
- Anger/ anxiety
- Holistic needs assessment
- A card for irradiated blood?

Working in partnership

- Insufficient co-operation between GP surgeries and specialist CLL clinics, leading to more extra work for both?
- Communication between specialist hospital and local hospital

What questions to ask, and getting information from healthcare professionals

- What questions should I be asking?
- Lack of communication from healthcare professionals.

Raising GP awareness

- Raising GP/ medical profession awareness about CLL (3)

Other

- Better monitoring of Health Unlocked
- Roadmap of how to access services in each NHS trust

2. "My clinic": examples of good practice

Three of the fourteen groups had no examples of good practice to report. Additionally, in a few groups, some of the members reported that their experience had been poor or disappointing.

There were a couple of instances of innovative practice.

Reading between the lines, it would appear that a good patient experience depends on the clinic having a full team in post. Hospitals, which have better resources, are able to offer a fuller service than those, which are short staffed.

Access to a clinical nurse specialist (CNS) for CLL, or for blood cancers, was critical to having a good experience of care. More information on this is given below in section 3: Access to a nurse specialist.

It would appear that a good experience is dependant in part on the patient being proactive in asking for a service: "*You have to ask for a copy of the letter to the GP."*

There was one instance of a partner having used her professional experience to instigate a collaborative approach with her husband's GP. She worked on adverse event reporting on Ibrutinib and got the backing of her husband's GP for her Research Centre to approach the GP for patient information. The message here is: take the initiative and use whatever clout you have to improve working in partnership, whether this be between healthcare organizations or between patients/carers and healthcare professionals.

Some group reports did not indicate the name of the hospital and its location for the examples of good practice they gave.

Innovative practice

- "Distance" clinic offered by Bart's hospital, London, through Skype, enabling face- to-face contact with specialist from patient's own home.
- Patient card with advice on vaccinations, to take to GP surgery and a letter from the clinic to the GP to establish partnership in the care of the CLL patient. Oxford.

Clinical Nurse specialist

- Access to a clinical nurse specialist (CNS) during clinics at University College London Hospital (UCLH)
- Immediate access to a CNS at the Royal Free Hospital, London.
- Card issued with CNS contact details at Royal Marsden, Sutton, Surrey site.
- Nurse specialist is brilliant. Several of them are always available. Broomfield Hospital, Chelmsford.
- Kings, London. There's a CNS if you need one.
- Good clinical nurse specialist at St Richards, Chichester

Management of blood sampling and results

- Fast turnaround of taking and analysing blood sample - one hour at UCLH.
- Blood testing done during the week ahead of the clinic appointment through a walk-in service, the patient having been given an order form to present. West Middlesex University Hospital (WMUH), Isleworth.
- One-stop clinic for blood test and consultation.

Good practice in providing information to the patient

- Receiving a copy of the letter sent to the GP after each consultation, but you have to ask to be sent a copy.
- Print-out of full set of tests and progression chart handed to the patient.
- Willingness to take on board useful guidance from CLLSA and to distribute to patients at Croydon University Hospital

A well-managed service

- Punctuality at Kingston hospital
- A text message reminder of appointments

Good facilities

- Chemo suite on site and very supportive. (Name of hospital illegible.)
- Coffee and lunch for patients attending clinic

A good consultant

- Positive consultants at Camberwell, London
- Consultants took time to holistically assess at Royal Marsden, Sutton site.

Regional support group

- A haematology group meeting monthly at Maggie's Centre, Aberdeen

Other

- Pre-clinic multidisciplinary meeting. Luton and Royal Marsden. *For info: this should be standard practice everywhere. Refer to explanatory note in the jargon buster issued at the conference.*

3. "My clinic": access to a clinical nurse specialist (CNS)

We wanted to get a snapshot of how many of the 49 patients in attendance in our discussion groups had access to a CNS, and how many of these were on watch and wait.

It would appear that 32 (65%) out of the 49 CLL patients present had access. Watch and wait patients are less likely to have access: 55%. The rate for those not on watch and wait was 88%. Can this be a reliable, indicative sample?

It is unexpectedly high. The findings of the 2016 patient experience survey undertaken by Leukaemia Care showed that 38%, in a survey of 2,019 leukaemia patients in the UK, had access to a CNS. The survey reported a range of 30% to 50% in different regions of England, and lower rates in Scotland and Wales. In their article "My CNS Matters: the invaluable role of the clinical nurse's specialist" Leukaemia Care report an increase of 19% in CNSs in England between 2015 and 2017.

There were various comments from our discussion groups at the London Conference about the difficulties of access experienced, even when there is a CNS. "*It's a struggle. They change a lot." "There is access, but they are difficult to find." " Yes, I did have access but after some unnecessary aggravation." "Never see her. Doesn't call back." "Not able to access by email and no response given to answer-phone message left".* Once again, it would seem that the patient who is prepared to be persistent, resourceful and demanding may get a better deal, but CNSs remain thin on the ground.

4. "The CLL Support Association": services most valued and why

As was to be expected, asking this question at a CLLSA conference resulted in the most frequent citation being: CLLSA Conferences.

Reliable and expert information; meeting others with CLL; support available through the Health Unlocked Forum and the Helpline; regular communication from the Association; the Ibrutinib campaign – all of these were services most valued by conference attendees.

Conferences
All groups mentioned this. They liked:

- Access to expert haematologists
- Excellent speakers/the quality of presentations/ expert, up-to-date information
- Being able to talk openly and at a level we understand
- Meeting and talking to others/ the human contact/hearing how others are dealing with different aspects and treatments/ gaining support from others at conferences/ " First time I have ever met anyone else with CLL."/ "Love meeting people."
- Knowledge and information sharing

The website
Five groups mentioned the value of the website to them. They like it for:

- The extent of the information there
- Being a useful resource to turn to
- Having a single point of information on CLL
- "It's useful to be alerted to information on the website. I have a folder for all the emails I have alerting me to the website content."

The Health Unlocked Forum
Four groups highlighted the Forum. They liked:

- Sharing everyone's journey
- Personal accounts of trials
- Travel insurance recommendations
- The daily digest of new postings
- "Health Unlocked is both good and bad. Sometimes informative."

The Helpline
Three groups commented on the value of the Helpline.

- It's always available
- It's good for support prior to treatment
- It's useful in moments of panic

CLLSA is a respected source of information

- A responsible source of information.
- A verified information resource

CLLSA provides a collective and effective patient voice

- The Ibrutinib campaign

5. "The CLLSA Support Association: priorities for CLLSA to address

Most groups approached this as a brainstorming exercise. A couple of groups had attempted to prioritise.

Much of what was proposed confirmed that CLLSA is already on the right track. It is either something we already do or is work in hand. *Information is given in italics below.*
Other proposals are difficult to realize, being beyond the capability or resources of the CLL Support Association.

This left a shortlist of priorities for the CLLSA Board of trustees to consider.

Proposals already in hand

- Deliver more conferences: *6 planned for 2019*
- Expand buddy scheme: *funds being sought to extend scheme*
- CLLSA Champion scheme: *a major drive for 2019*
- Code of practice for initial diagnosis: *project in hand with Leukaemia Care and*

consultants

- Recruitment trustees: *three potential applicants came forward at the Conference*
- Stronger pressure group to government: *Being handled by All Party Parliamentary Group (APPG) for Blood Cancers, of which we are members.*
- Greater awareness amongst politicians about CLL: *see bullet above*
- Up-to-date information: *new member booklet being written, available June 2019*
- Keep talking to CNSs – get the message across: *CLLSA is hosting the next meeting of the newly inaugurated CLL Nurses Forum at the CLLSA Conference in March 2019.*
- Information on access to newer treatments: *in new member info booklet June 2019*
- Work with other blood cancers: *CLLSA is one of ~~12~~ blood cancer charities in the Blood Cancer Alliance*
- Get CNS specialist to give talk on role: *a regular feature of CLLSA conferences. Look out for the presentation at Liverpool January 2019; it will be put on web in February.*
- Access to trials: *in new member info booklet June 2019*
- Greater awareness of CLLSA by healthcare professionals: *being addressed by CLLSA profile raising champions*
- Consider membership fee: *very thorough consultation exercise in 2017 resulted in decision not to introduce a fee for the time being*
- Explaining CLL in simple language: *in new member info booklet June 2019*
- Guide for telling family: *in new member info booklet June 2019*
- Support/guide for mental health: *will feature at a presentation at Cambridge CLLSA Conference in March 2019. Look out for the video on our website in April 2019.*
- Wider exposure to GPs: *part of the remit for our profile-raising champions.*
- Advice on managing fatigue: *Leukaemia Care have run a series of workshops on this and may be able to advise.*
- Start a UK Facebook Forum: *Health Unlocked Forum already working very well, with very high UK membership*
- Information on which vaccines to have: *in new member info booklet June 2019*

Proposals difficult for CLLSA to realize

- Swifter access to treatment: *Parag Jasani alerted us at the Conference to this issue being on the table for the clinical community.*
- Deliver more local support groups: *as a national charity with limited resources we have to rely on members to launch and run local groups with CLLSA support*
- List of centres of excellence throughout the UK/ Map haematology centres across UK: *some resistance to this from the clinical community. We have tried.*
- How to access personal profile: *was this a reference to information on healthcare professionals? If you know the name, there is often info on the web.*
- Need for directory of local CNS support: *constantly changing and not held by NHS.*

Short list of proposals for CLLSA Board of trustees to consider

- Fundraising: away from pharma; encourage regular donations
- Update the website
- Raise CLLSA profile

6. "The CLLSA Support Association": difficulties experienced as members of CLLSA and what CLLSA might do about them

The question: "What, if any, difficulties have you experienced ***as a member of the CLLSA****?*

was misunderstood by many. Groups tended to reiterate in their notes what they had already reported earlier under “priorities for CLLSA to address”. Three groups wrote: “no difficulties experienced”.

There were two triggers for the question. We had frequently heard that navigation of the CLLSA website is not easy. Secondly, a few members had told us that they were considered by healthcare professionals to be over-informed and as a consequence asked too many questions. We wanted to know if this had been the case for our attendees at the London Conference. We received no feedback in response to these two triggers.

However, it was reported independently afterwards that Dima El Sharkawi, consultant haematologist and our keynote speaker, had urged members in the discussion group she attended not to be discouraged, but rather to persist and ask any questions they had. This, we might add, is a mark of a good consultant.

Where groups’ feedback made comments already logged, we consider then to have been adequately covered already in this summative report.

The leaves a short-list of shortcomings raised for CLLSA trustees to consider:

- An opportunity to talk to CLL patients of my own age (42)
- Benefits system, sign-posting to help
- Good advice on a managed life style

Dima’s advice apart, our follow-up question: “What can we as an Association do about these difficulties? “was not answered.

Concluding comments

This was an ambitious consultation exercise, not fully pulled off. Answers to open-ended questions are difficult and time-consuming to analyse and there was much repetition, as well as difficult handwriting to decipher.

Nevertheless, a rich picture emerges of the patient experience.

It is reassuring for trustees to have confirmed from members that we have correctly assessed many of their needs.

Hopefully, our members will read this report and learn more about what CLLSA is doing to address the concerns they raised. (Four paragraphs responding to members’ issues, pages 1 and 2, and Proposals already in hand, page 6.) The new and more frequent e-bulletin should help to get the message across.

We have teased out a short list of 6 items, put forward at this London Conference, as priorities for the CLLSA Board of trustees to consider:

- Fundraising: away from pharma; encourage regular donations
- Update the website
- Raise CLLSA profile
- An opportunity to talk to CLL patients of my own age (42)
- Benefits system, sign-posting to help
- Good advice on a managed life style

Olga Janssen
16 November 2018

Dr Dima El-Sharkawi – Responses to outstanding questions from Q & A

I would like to thank you all again for inviting me to speak at the CLL SA London Patient Conference. I really enjoyed my day and learnt a lot myself during the day. I am sorry I didn't have time to answer all your questions following my talk- I did get to speak to a lot of you throughout the day, so hopefully answered most the questions then. But I did promise I would write to you my opinion on the questions that you had written down. I have grouped them into broad categories for ease of filtering through them.

Lots of interesting questions, and I should state that my answers this year may not be the same as if you ask me the same question next year, as evidence changes our opinions. You should always consult with your own doctor regarding your particular circumstances and seek their opinion.

TREATMENT

Does Rituximab and ibrutinib make sense as front line treatment for P17/TP53 deleted patients?

There is now a lot of long-term evidence that those patients with TP53 deletion do less well with "standard chemotherapy" than those who do not have the deletion e.g. CLL8 study in which 22 patients with TP53 aberration (mutation or deletion) were randomised to the FCR arm, and in whom half had progressed within 2-3 years.

The evidence for ibrutinib in this cohort of patients is compelling- in a single arm phase 2 study in patients with TP53 aberrations (33 previously untreated patients and 15 patients who had previously been treated but have since relapsed), the progression free survival at 30 months (how many patients have not progressed or relapsed during this time) is over 80% (Farooqi, 2015).

Both rituximab and ibrutinib have been shown to have activity in CLL, and so there have been trials looking at whether adding rituximab to ibrutinib improved the time until the disease progresses (PFS, progression free survival). One of the larger studies was reported in ASH in 2017 when the PFS did not improve with the addition of rituximab. However, they did note in this study that the patients who had both drugs achieved a quicker and deeper response. (http://www.bloodjournal.org/content/130/Suppl_1/427). Also, it should be noted that the results in the abstract look at the whole cohort, and does not provide information on P17/TP53 deleted patients specifically.

When do you decide a patient needs a stem cell transplant?

As when deciding on any treatment, we look at patient related factors and disease related factors. Whilst allogeneic stem cell transplant (receiving someone else's stem cells) can potentially cure some people of CLL, it is also can be a toxic treatment with a small risk of death or significant organ toxicity. The risk of toxicity is dependent partly

on “fitness of patient”- do they have any other medical problems, how well is the patient generally, age of patient (although there is no strict cut-off with age). Given the number of newer therapies that are effective in CLL, this has led to the number of stem cell transplants being done nationally decreasing. However if patients are deemed fit enough and have poor risk disease, i.e. they have relapsed/ progressed through most standard lines of treatment, then it may be considered.

Idelalisib- is it still used? Side effects? Is it safe to stop if I am in remission?

I apologise that I did not have time to cover idelalisib in my talk.

It is still used but less frequently started in patients due to the incidence of infections seen with this drug, but nevertheless it is still an effective drug.

The current NICE approvals for idelalisib in combination with rituximab are for those who have TP53 aberration who cannot have other targeted agents, or in those patients who have relapsed within 24 months.

Some people may have started it before the current recommendations and they would be able to continue to receive it for as long as they are getting benefit and acceptable toxicity levels.

Side effects: liver dysfunction, rash, diarrhoea, colitis, pneumonitis.
https://www.medicines.org.uk/emc/medicine/29201

With all targeted inhibitors including idelalisib, we don’t have enough experience to know when, or if ever, it is safe to stop them. A lot of studies are looking into this very question currently, but until we have more data, the advice we continue to suggest is to carry on taking the drug for as long as you are deriving benefit and not getting undue toxicity. The latter part of this sentence is subjective, and will need discussion between you and your haematologist regarding the side effects.

Survival rates for those that are significantly younger than average?

As you are aware, the median age at presentation of CLL is 72 years, that means half the patients diagnosed with this disease will be older than 72 but half will be younger.

There are no trials that I am aware of that look specifically at treating patients that are very young, although different groups have published the outcomes of patients who are less than 55 years.

An example of this is a single US centre published their experience of patients with CLL who are less than 55 yrs at diagnosis (over 800 patients). This may not reflect the true population, as given this is a specialist centre, patients with difficult or aggressive disease may preferentially get referred to this centre. What they found was that younger patients were more likely to be IgHV unmutated compared to the older population, and the time from diagnosis to treatment was on average shorter.
http://www.haematologica.org/content/99/1/140.short

How do you get onto a trial?

If there is a trial suitable for you, you should be able to discuss it with your medical team at your hospital. If there is a trial that you could be suitable for that your hospital is not participating in, then you could discuss with your medical team whether they could refer you to a centre that is running the trial to at least discuss it with them. There is currently a large national trial for frontline therapy (i.e. first treatment for CLL) called FLAIR that is randomising (fit) patients to either standard chemotherapy, ibrutinib or ibrutinib containing regimens. As this is randomised, neither you nor your medical team would get to choose which treatment you have, this would be allocated to you randomly.

Before participating in any trial, the medical team will explain the trial in detail and give you written information regarding the trial for you to think about it. If you agree to go ahead, then you would need to undergo the screening tests and the medical team would need to confirm that you fulfil all the eligibility criteria before they could confirm that you are able to go ahead with the treatment.

You are able to search what trials are running and in which centres in the UK and worldwide on different websites.

This is a link to the database that is updated by the lymphoma association charity:

https://lymphoma-action.org.uk/find-a-trial

This is the link to the US website run by the national library of medicine- it is a very comprehensive list of trials, although sometimes it is slightly out of date in terms of whether the trial is still recruiting patients or not. https://clinicaltrials.gov/

This is the link to the NIHR database of trials being conducted in the UK.

https://www.ukctg.nihr.ac.uk/

Any trials for familial CLL?

I am not aware of any trials in familial CLL that is looking specifically at the treatment of patients with a strong family history of CLL or other lymphomas as, given the rarity of this, it would be difficult to do a trial that produced meaningful results. Patients are of course eligible to enter trials for CLL whether they have familial CLL or not.

Families which have a strong history of CLL or other lymphoid malignancies can give us clues as to which genes may be contributing to this risk and so we can learn about the biology of the disease through studying these patients and families, and various groups are looking at things from this angle e.g. https://dceg.cancer.gov/research/clinical-studies/blood-cll-info

ALTERNATIVE TREATMENT

Will medical cannabis be any good for CLL?

Short answer is: don't know.

Medium length answer is: most Doctors (including myself) aim to practice evidence based medicine, that is to say we only recommend treatments which have been trialled and for which we have definite evidence or proof to say that they are likely to work. There are lots of medicines and alternative treatments which could potentially have some effect but if there is never a trial to prove it, we cannot recommend it.

Longer answer is: There is only one trial on CLL cells in a laboratory that I could find that explored the potential effect of cannabinoids on CLL which suggested that perhaps it wouldn't have much benefit.
https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0156693

VACCINATIONS

What advice do you give regarding being around grandchildren having vaccinations?

I work in a school, the children are getting live flu vaccines, should I be around them?

We suggest to patients with CLL to avoid having live attenuated vaccines as there is a small risk of developing significant infection related to the vaccine as a consequence of the immunosuppression related to CLL.

Given that many children are now having a live attenuated flu vaccine that is given via nasal spray, there is a concern that these children may shed the virus a few days after vaccination, however this virus is likely to be in small amounts, and also is less able to spread from person to person to cause an active infection and so the risk for patients with CLL who are around people who have had the vaccination is extremely small.

Public Health England and the Advisory Committee on Immunisation do not suggest that you need to avoid seeing others who have had the live vaccine recently unless you are severely immunocompromised.

http://www.oxfordahsn.org/wp-content/uploads/2015/07/PHE-factsheet-for-HCW-andheadteachers-on-LAIV-concerns-about-viral-shedding.pdf

https://www.ncbi.nlm.nih.gov/pubmed/18662737

Would you advise me to have the Shingrax vaccine?

The standard shingles vaccine given in the UK is a live attenuated vaccine and thus should be avoided if you have CLL.

Shingrix is a vaccine for shingles that is recombinant i.e. Not live. However, it is not currently licenced in the UK, but I understand it is under consideration for future use so may be available in the UK at some point.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/696498/Shingles_information_for_healthcare_professionals.pdf

I understand that it is available privately in some units, I would discuss with your own haematologist the risks and benefits for having or not having a vaccination and the

timing of the vaccination as the decisions with regards to this are personalised to your circumstances- but in general, it would be useful to decrease the risk of shingles.

If I have only had the adult pneumonia vaccine should I get the PC13 one as well?

It is known that patients with CLL develop a better immune response to the PCV13 vaccine compared to the standard adult PCV23 vaccine. Current UK guidelines is to have Prevnar, PCV13 followed by PPV23 at least 2 months later. If you have already had the PPV23, then the Department of Health recommends that you should wait at least 6 months before having the PCV13.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/674074/GB_Chapter_25_Pneumococcal_V7_0.pdf

IMMUNE COMPLICATIONS OF CLL

Can CLL make anaphylaxis more dangerous?

Anaphylaxis is an emergency as it is a severe allergic reaction to something that can be life threatening. So, having CLL won't make anaphylaxis more dangerous as it is already potentially life-threatening. However, there does seem to be a link between allergy and haematological malignancies, one population study found that those who have allergies were at slight increased risk of haematological malignancies.
https://www.sciencedirect.com/science/article/pii/S0145212614002379

Can having CLL increase the risk of all infections?

Yes, we know that CLL can affect the immune system in many different ways, and so can the treatment for CLL. This does lead to an increased susceptibility to all types of infections and increases the risk of severe infections.

OTHER COMPLICATIONS OF CLL

Can liver problems be a side effect of CLL?

Is squamous cell carcinoma, polymyalgia, coeliac disease related to my CLL or treatment (idelalisib)?

The short answer to all questions asking whether another disease or symptoms is related to the CLL, is: it could possibly be related but not necessarily so.

Specifically, with regards to liver dysfunction:

CLL can directly infiltrate and affect the liver- the chances of this occurring are unknown but in one study, it was shown that approximately 1 in 20 patients who had CLL and who had not had treatment had abnormal liver function tests (blood tests).
https://onlinelibrary.wiley.com/doi/pdf/10.1002/ajh.24915

We also know that a lot of the treatment we give for CLL can also affect the liver.

Also, as I discussed during my talk, people with CLL are at increased risk of infections and autoimmune complications both of which can potentially affect the liver. However, I am not aware of an increased risk of autoimmune liver conditions with CLL, . Although there are occasional case reports of patients having both, that does not necessarily prove that one was related to the other.

I am not aware of an increased risk of CLL in patients with polymyalgia or coeliac disease or an increased risk of these conditions in patients with CLL. Coeliac disease has been associated with an increased risk of some types of lymphoma.

The increased risk of skin cancers including squamous cell carcinoma in patients with CLL has been well described in the literature. However, most patients with CLL won't get skin cancers, it is just that the risk in this population is higher than in people who don't have CLL. There are lots of reasons that have been proposed for why there may be a link including the altered immunity, shared genetic susceptibility.

Idelalisib is very well known to cause abnormalities in liver function, however it is a relatively new drug so although I am not aware that it directly increases the risk of autoimmune conditions or other cancers, we would need to get a lot more experience before we may be able to identify rare side effects related to the newer drugs.

What medical screening would you advise?

There are no specific screening recommendations in the UK for patients that have CLL that is different to the general population. What I would suggest is that if you are invited to do any routine screening investigations e.g. breast/ bowel that you attend. Secondly, I would suggest you look for and monitor skin lesions or ask your Doctor or haematologist to look at a lesion if you are concerned about it. Final thing is that if you smoke- stop smoking, and if you need to support to do this, then you can ask at your GP surgery or hospital what support is offered.

OTHER

Can clonal lymphocytes infect someone else through blood contamination e.g. a first aider handling a wound without wearing surgical gloves?

As a general point, the skin is an excellent barrier to contagious blood borne diseases being passed from person to person, so as long as the first aider in this scenario did not have any open cuts, the likelihood of getting any blood borne infection would be minimal.

Specifically concerning CLL- it is not a "contagious" disease. Although there can be a lot of clonal lymphocytes in the blood of a patient with CLL, there is no evidence that this can "infect" another person. In fact, one study looked at almost 800 blood donors in Denmark and Sweden who subsequently were diagnosed with CLL and looked at the outcomes of over 7000 patients who received blood products from these donors, to see whether they had an increased likelihood of developing CLL over other patients who had received blood transfusions and they did not.

http://www.bloodjournal.org/content/126/17/2059?sso-checked=true

What factors cause the CLL cells to sometimes increase or decrease?

Lots of factors can cause peoples lymphocyte count to go up and down, some of which we know and are predictable, for example disease progressing or being treated. Other times we see patient's lymphocyte count go up during an infection, and we worry that it is a sign that the disease is progressing and then it goes back down once the patient recovers from the infection. There are also lots of reasons we can't explain, which is why we wouldn't look at one change in isolation, and look at the general trend of the lymphocyte count over a number of blood tests. Also, in practice decisions regarding when to start treatment for a patient is usually based on falling normal counts such as Haemoglobin and platelets rather than white count increasing alone.

Finally, there are lots of variables in checking bloods, so if I took 10 separate blood tests from one patient at one time, there would be some variability in the results we get.

Appendix 6

CLL Support Association Conference – London

Thursday 8th November 2018
Victoria, 1 Drummond Gate Pimlico, London SW1V 2QQ
See website for details: https://www.etcvenues.co.uk/venues/victoria

Programme

10.00 a.m.	**Arrivals, refreshments, meet table companions**	
10.30 a.m.	**Welcome and introduction to the day**	Marc Auckland
10.40 a.m.	**Members' CLL stories** A patient's and her friend's perspective	Sue Cracknell & Elizabeth Pearson
10.55 a.m.	**CLL, Treatment now and in the future** Dr Dima El-Sharkawi is a Consultant Haematologist at the Royal Marsden Hospital with a special interest in CLL and lymphoid malignancies and haematology malignant diagnostics. Her clinical research interests focus on the translation of scientific advances into clinical practice, and she is an investigator on a number of clinical trials.	**Dr Dima El-Sharkawi**
12.40 p.m.	**Lunch**	
1.40 p.m.	**Update on CLL Support Association developments**	David Innes – Chair of CLLSA
2.00 p.m.	**CLL Support Association champions** Focus on Role Profile Raising Role and identifying volunteers	Roger Huxley
2.20 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
3.15 p.m.	**CLL 'Cure'?** *Dr Jasani is a Consultant Haematologist at the Royal Free London and University College London Hospitals NHS trusts. His special interest is CLL and Lymphoma. He is a member of CLL clinic at UCLH. He is also a Principal investigator for various clinical trials for CLL.*	Dr Parag Jasani
3.55 p.m.	**Conferences closes.** Conference reports and slides	Marc Auckland