

Report on the CLLSA Newcastle Conference, 19th July 2019

“Scott was super. Excellent relevant information!

All was great, thank you so much!”

Report Introduction

Above is a sample of the highlights from the 50 members who attended the fourth of this year’s four scheduled conferences. It was held at the Life Science Centre, Newcastle upon Tyne. Key speakers were:

1. Dr Scott R Marshall, Consultant Haematologist Sunderland Hospital also Clinical Lead on CLL and trials for the North East.
2. Members’ Stories – Bethan Cawley and Alice Scanlon.
3. Marc Auckland, CLLSA Chair. National CLL Survey results and Association Update.

The conference included a CLLSA update and member workshop. This involved attendees considering what members need from the CLLSA and feedback on the CLL Survey results.

The report is based on attendee feedback and is prepared for the speakers, CLLSA trustees, conference facilitators and volunteers, attendees, LeukaemiaCare and Lymphoma Action representatives and all 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
- Summary of sessions
- Appendix 1. Composition of attendees
- Appendix 2. Analysis of feedback form returns
- Appendix 3. Analysis of group discussions’ feedback on members’ issues, their CLL clinics and what they want from the CLL Support Association.
- Appendix 4. Conference Programme

What worked well

- Guest speaker content and opportunity for Q & A
- Event organisation and use of plasma screens
- Meeting fellow members and learning together

What could have been better

- Shorter patient stories
- CLL research edited down with less detail on slides so more readable
- Room was cold

Session summaries

95% of members completing the feedback forms rated speaker presentations as excellent. Attendees feedback rated the presentations as excellent or good. All written feedback is listed in appendix 2 with illustrative quotes included in the commentary below.

Patient Stories

We opened the conference with the traditional members' CLL stories. Bethan Cawley has been a CLL patient since 2015. Bethan is an active member who raises funds and lives in the North East with her family. Bethan shared the impact, physically and emotionally both on her, her family and friends and career. In 2015 Bethan had changed her Job, celebrated her 50th birthday, a family wedding and been diagnosed with CLL. She experienced many highs and lows; Swollen lymph nodes caused much pain and she had difficulty getting information about CLL and prognosis for the future. Initially on Medical Monitoring (Watch and Wait), she moved quickly to treatment, FCR, in July 2016. Bethan found CLLSA and Health Unlocked forum very useful in this period. She even met up with forum members in London to celebrate recovery. We then heard from Alice Scanlon and her husband Tony. Alice is a retired local government officer. She was diagnosed with CLL in November 2018. Alice lives on the East Coast with husband Tony. She is keen to set up a support group in East Yorkshire. Alice is only recently diagnosed and on Medical Monitoring still. Alice too went through the shock of diagnosis and seeking information, again fortunate to connect with the association and learn more about disease and treatment. Alice is keen to help set up a support group so others in her area can meet, support each other and help newly diagnosed patients get access to local support. Tony shared the experience of supporting a loved one, offering support, monitoring fatigue and just being there. It was clear Tony is a great support for Alice and demonstrates the value of a partner, loved one, close friend to support the CLL patient on their journey.

Feedback included: *'Best was patient stories, patient stories good'*

Patient Research

Marc Auckland presented a seminal piece of research conducted in partnership with Janssens Pharmaceuticals. The objectives were to:

- Understand how CLL affects patients, their lives and those around them, through their journeys.

- Explore how management of CLL could be improved from the patient point of view and what a good interaction with their HCP (Health Care Professional) is.
- Explore how managing and treating people with CLL is affecting patients both rationally and emotionally.
- Explore the treatment pathways, build upon current haematologist, oncologist and specialist nurses' beliefs and behaviours for treating CLL, including any gaps in their needs.
- Explore how HCPs communicate treatment options to patients and how the treatment pathway is framed.
- Understand the considerations HCPs make in the treatment decision and the extent to which patient parameters come into consideration or could play a role in the future.

Marc explained that carefully selected HCPs, CLLSA patients and partners from around the country were interviewed in Manchester or London. This was followed by an individual interview at home. A range of HCPs, in practice for at least two years, seeing at least 8 CLL patients a month were selected and interviewed. CLL patients and partners/carers selected were either on Watch and wait, a course of treatment or in relapse.

Key Observations highlighted a number of differences between the patient and HCP perspective, which, if addressed, would provide a smoother journey for patients and supporters.

- Clear explanation of the disease especially the term Chronic. Understanding of current treatments and outcomes. Education of HCPs and supply of information to them, plus the sources of help and support for CLL patients.
- The need to create and supply resources to new patients to improve their understanding of the disease, treatment options, resources available.
- Clear explanation of the patient care team, roles, availability so that the patient feels involved and reassured.
- Ensuring all patients have access to a nurse and/or support available via associations.
- The need for clear, consistent, up to date information, leaflets, website and other channels known by HCPs and patients.
- An increasing awareness of CLLSA with HCPs and importance of peer to peer support for patients.
- The necessity of more time available to patients to raise questions and concerns particularly at diagnosis which will shape their view of the disease going forward.
- The importance of knowing the level of information individual patients want in order to tailor advice and support.
- Nurses, even through external sources, available to answer questions.

Marc walked through the research. Table groups discussed the findings seeking feedback from attendees. Do the findings resonate with their journey and needs? Are there gaps and do they support the recommendations going forward (listed below), and detailed in slides 19 and 20 of the market research slides.

Key Research Recommendations.

- 1. Communicating education around diagnosis**
Importance of diagnosis discourse and how this impacts patient's future view of CLL. HCPs may have lower engagement with CLL than other malignancies but to the patient it is everything. **Educate on emphasising 'chronic'** and contextualising CLL. Set honest expectations.
- 2. Raise awareness of CLLSA** amongst HCPs and encourage dissemination to patients. Consider **reviewing CLLSA offering alongside Myeloma UK** (the Haematological malignancy gold standard). Provide clear **CLL specific information**; encourage HCP direction rather than general cancer sources.
- 3.** Educate HCPs around importance of explaining **care team** and, particularly, why patients will see different Haematologists. **Simple leaflet** to explain how the general NHS referral pathway works would help. Ideally followed by a simple discourse from HCPs to provide reassurance to patients
- 4.** Use '**active monitoring**' instead of 'watch and wait'. Ensure longer term patients are reminded and reassured about the premise of this period and see it as a positive. **Provide materials around what relapse means.** Consider avoidance of using 'relapse' within discourse.
- 5.** Review materials related to targeted agents to **ensure they are fully comprehensive in relation to side effects** and management of side effects. Share **positive stories about targeted agents.** Create an **information tool** (e.g. website) to aid patient education and disease awareness amongst HCPs.
- 6.** Provision of / education around **support & helpline** for patients, especially where nurse not available
- 7. GP education** to ensure diagnosis discussed in a clear and accurate way. Emphasising importance of accurate discourse at diagnosis, relapse and understanding of CLL.
- 8.** Develop **peer-to-peer support** services.
Consider wider use of **buddy schemes** to support patients.
- 9.** Develop information **videos – patient stories** at different disease stages, particularly around relapse. Using language to educate HCPs and patients alike.

Members circulated over lunch, networking, visiting the Myeloma UK and Leukaemia Care stands. They also had the opportunity to talk to the expert speaker, Dr Scott Marshall, who arrived over lunch and joined members at their tables during the break out table sessions first thing in the afternoon.

CLLSA Update

Marc Auckland opened the afternoon programme with a CLLSA update.

A membership milestone has recently been achieved with membership exceeding 3,000. The Health Unlocked CLLSA forum which is worldwide, now has over 12,000 members. Six regional conferences will be achieved this year for the first time in our history. We have recently launched an under 60s group at the Bournemouth conference in answer to member requests.

Two new trustees have been appointed with a further two in the pipeline that will bring us back to full strength. The new ebulletin to members has been launched and has received positive feedback. We now have over 100 champions across the country volunteering to raise awareness of the association at their surgeries and hospitals. Knowledge of the association is low with medical professionals and patients so this is a vital service. Attendees were invited to sign up to become champions.

Marc thanked all for fundraising activities as funding is critical to keep membership free and maintain the current level of activity. He asked for all to let us know of any fundraising activities planned so we can promote through the website and e bulletins.

Marc also thanked those who partook in the flash fundraiser for a new state of the art laptop for conferences, the old one can now be retired!

Thanks to a will bequest we are in the process of rebuilding and relaunching the website. The new site will be opened before Christmas and will use latest technology to provide conference booking, member emails and self-service donating. A new members pack, updated with the latest information will be launched at the same time.

Finally, he shared examples of the advocacy and lobbying activities. From membership of the Blood Cancer Alliance, through new trial and drug petitions to NICE (National Institute for Health and Care Excellence) and meeting with the Appg (all party parliamentary group - Health) to increase political awareness of CLL. They were all to raise awareness of member needs and influence/improve treatments available to members,

Member Round Table

This was an opportunity for members to share their own experiences and best practice at GP Surgeries and Hospital Clinics. They also built on their views on the research recommendations shared in the morning to identify what their association should build on moving forward. See Appendix 3 for feedback summary.

Expert Speaker

Dr Scott Marshall then gave his expert speaker presentation. Scott qualified as a doctor from Edinburgh University in 1996 and worked in London and the South East before settling in the Northeast. He has always been interested in the immune system, taking a degree in Immunology at Edinburgh and later undertaking a PhD in Immunology and Transplantation at Newcastle University. Scott became a Consultant Haematologist at City Hospitals Sunderland in 2008 and is the lead for the Clinical Trial Research team since his appointment. He also contributes to local laboratory research projects in Newcastle. Scott is also the Clinical Lead for CLL in the Northeast and a member of the UK CLRN CLL Clinical Trials committee. Scott has recruited many patients to clinical trials in CLL and other diseases. He was appointed Clinical Director for Medical

Specialities at Sunderland in 2013 and shapes services in the South of Tyne but also continues as a Consultant Haematologist as his main role.

The title of his talk was 'CLL – What should I know now that I have it, what treatments are on offer and what might the future hold?' Scott opened by defining CLL. Stating CLL is 1% of all cancers and 40% of blood cancers. Around 3,500 people are diagnosed annually with about 100 in the North East of the UK. It affects nearly as twice as many men as women with the median age of diagnosis as 76. Scott felt that the assumption that CLL was a western disease was a myth purporting that it exists in East and Africa for example but is often misdiagnosed.

Identification of CLL 30 years ago was down to a trained eye and a blood smear under a microscope. Over the last 3 decades technology and research has allowed much more accurate diagnosis and profiling, it is now more about patterns in how the disease presents. This profiling of the disease and of the patients age, fitness, co-morbidities etc and the increasing range of treatments allows for much more tailoring of treatment pathways.

Scott explained both the American and European staging systems and their use to measure key indicators of the disease progress. He emphasised the need for health diet and exercise as well as vaccinations.

Scott moved on to talk through the development of treatment pathways over the past 30 years. He then talked about the IWCLL 2008 criteria for treatment which is used in all trials as well and day to day monitoring of patients. He reiterated with the more accurate disease and patient profiling and new drugs; tailored treatment pathways are becoming more available.

Scott summarised 1st and 2nd line treatment pathways using the various recent trials that have used the newer drugs, to demonstrate the increasing progression free survival rates even for mutated and related disease profiles. Scott concluded his talk with his view on the future with more use of the drugs such as Ibrutinib and Venetoclax plus a 'cocktail' of combinations to manage the disease. He considers that this will allow the patient to continue to live for many years with CLL and probably die of a secondary or unrelated morbidity.

Feedback included: *'Best was listening to Scott Marshall'. 'Scott was superb'. 'Good keynote presentation, well pitched'.*

Shirley Emmerson from CLLSA's sister charity LeukaemiaCare and Karen Bonnell from the Lymphoma Association 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.

Meeting fellow members

Attendee were allocated table groups based on their post code to try and encourage local contacts where possible. Some of the member facilitators led tables as they wanted to form local groups. In the breakout groups members helped contribute to the development of the CLLSA and its work to raise its profile.

Feedback included: *'Table discussion best, Discussions, left with a positive note', 'Trustee on table best', 'meeting and learning together'*.

Organisation and timing

The conference agenda was busy and required a short notice change to the agenda and content. Lack of preparation time hindered the quality of the research presentation. Overall timings and balance of sessions well received by members. Positive feedback was received for the information in the packs such as the jargon buster.

Table seating and venue

The venue facilities and location achieved the highest feedback score of 96%. Venue was airy, location close to hotel and railway station and the secondary plasma screens halfway down the room appreciated by members.

Feedback included: *'Lovely facilities', 'room cold'*,

50 out of 55 attendees booked turned up. The 5 no shows have been emailed to ascertain they are well and did not show because of an issue with the conference organisation or event.

Marc Auckland
2nd August 2019

Appendix 1

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 Newcastle Conference July 2019

Attendees:

Total places booked	55
Total in attendance	50
Cancellations before the day	8
Cancellations on the day	0
and no show on 19/07/19	5
Waiting list, not accommodated	0

Late cancellation/no show 5/55 = 9% 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.

First time member attendees	19 (56%)
Returning member attendees	10 (29%)
(Unknown status members	(5) (15%)
Total members	34*

**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 and 49.5% in 2018 (4 conferences).

Trustees: MA; BG; NG; DI; OJ; LT	6
Healthcare Professionals:	
Clinicians: SM	1
Charity Reps:	
Leukaemia CARE:	
Myeloma UK	2

Analysis of returned feedback forms from participants

Satisfaction levels for each aspect measured at Newcastle, 19 July 2019

	Not so good	Fair	All respondents			Total responds	%*	% 1 st time attend	% 2 nd plus attend	% 2018 all 4 conferences
			Average	Good	Excellent					
Advert, register	0	0	0	11	23	34	94%	95%	94%	90%
Location, facilities	0	0	0	7	27	34	96%	98%	96%	92%
Event materials	0	1	1	10	22	34	91%	87%	96%	89%
Group discussions	0	0	2	12	20	34	91%	89%	94%	86%
Presentations	0	0	0	8	26	34	95%	96%	95%	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 34 completed feedback forms, from a total of 50 attendees i.e. 68% return. We aim for a minimum return of 60% to be confident of findings. Trustees, (6) CLL coordinator (1) and visiting speakers (1) do not complete a feedback questionnaire. Charity reps (2) sometimes do.
3. Of the 34 completed feedback forms, 5 did not indicate whether they were first time attendees. Of the remaining 29 returns, 19 were from first-time conference attendees, i.e. 66% This compares with Bournemouth (May 2019) 71%; London ((November 2018) 36%; 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

34 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

12 respondents identified the expert speaker as the best aspect of the conference.

Listening to Scott Marshall.

Scott was superb.

Presentation by Scott Marshall.

Scott Marshall.

Dr Scott Marshalls presentation.

Dr Marshalls presentation.

Scott Marshall.

Presentation by Scott Marshall.

Marshall was very helpful.

Presentation by Scott Marshall.

Good keynote presentation, well pitched.

*Best was talk of future treatments.
Q and A session best.
Patient stories best.
Patient stories.
Patient stories.
Research.
Presentations.*

Meeting other CLLers and member workshop

10 respondents stated the meeting other CLLers was best.
*Being able to meet others with CLL and discuss.
Conferences essential, it brings comfort to my wife to know she is not alone, information is first class.
Discussions best, left with a positive feeling.
Meeting others best.
Meeting others with CLL/SLL.
Making contacts and networking best.
Discussing experiences with our CLL patients and partners.
Meeting other CLL patients.
Meeting other CLL folk.
Meeting others with CLL. Learning together.*

Conference facilities and Organisation

*Lovely facilities, lunch delicious!
Attending and info provided.
Informative handouts in packs
Jargon buster good.*

Least liked

18 of the 34 respondents left this question blank or simply wrote "nothing", "N/A" or "all good!"

Presentations

*diagrams pictures not tiny words.
Research PowerPoint slides.
Interpret the graphs or see them very well.
Slides difficult to see from the back of the room.
Research slides need to be edited down, difficult to see.
Unable to read slides.
Small advice given to younger people as it is perceived as an older person's illness.
Patient carer stories too long and repetitious.*

Meeting other CLLers and member workshop

*One general comment was: "Should partners be put on different tables so they each receive different things to discuss later?"
Meet more people.
Sharing experience*

Conference facilities and Organisation

More advertisement needed

Slides difficult to see from the back of the room.

Lack of daylight in venue.

Long afternoon.

Unable to read slides.

Screen presentations too small, room cold.

CLL research slides need to be edited down, slides too detailed.

Cold room pre-lunch.

The food (I'm fussy!).

Coffee cups too small.

Temperature in the room.

And awareness of the s-a (?).

CLLSA Newcastle Conference 19 July 2019

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.

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"

- Travel Insurance costs and options
- Immunity system improvement, research and advice
- People experience of the 'buddy' service
- What vaccinations?
- How to look after your self on watch and wait.
- Time with grandchildren.
- SLL & CLL clarification.
- What information is key for different stages?

- How do I tackle fatigue?
- Managing anxiety.

2. “My clinic”: examples of good practice

Two of the eight table 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.

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

Innovative practice

- Bloods taken at local GP, processed before Specialist appointment, saves travel and time.
- FLAIR trial providing with an information card, use when Infection, temperature necessitates A&E who fast track you to a sperate room for treatment.

Clinical Nurse specialist

- Access to a clinical nurse specialist (CNS) during clinics at Sunderland Phoenix outstanding.

Management of blood sampling and results

- James Cook University Hospital, Fast turnaround of taking and analysing blood sample – Weighed, Blood Pressure, CNS checks any issues, illnesses, symptoms then through to registrar for physical examination then informed of blood results. Normally takes no more than 2 hours.

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.

A well-managed service

- Sunderland Phoenix Unit team, outstanding.
- James Cook University Hospital, a benchmark service.

A good consultant

- Positive regarding consultant at Wrexham Hospital

“My clinic”: access to a clinical nurse specialist (CNS)

We wanted to get a snapshot of how many of the 50 patients in attendance in our discussion groups had access to a CNS, and how many of these were on watch and wait. 5 tables responded. 9 patients had access. Watch and wait patients are less likely to have access

There were various comments from our discussion groups at the Newcastle 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.

3. “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 and lobbying – all of these were services most valued by conference attendees.

Conferences

Four 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/
- Knowledge and information sharing

The website

Two 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
Glad it is being updated and relaunched

The Health Unlocked Forum

Two 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.”

E bulletins

Two groups commented on the value of the Helpline.

- Timely
- Reminder of progress
- It’s useful in moments of panic

CLLSA is a respected source of information

- A responsible source of information.
- Links to other resources
- Access to and value of the buddy scheme

4. “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.

Grouped Priority Requests

- Keep information up to date and better website, hard to navigate and post on: *refresh of website, info pack and e bulletin*
- More on new treatments; *Website and ebulletin will provide more info on developments and trials*
- How CLLSA works with other Charities;
- Support Groups; *will signpost via website and ebulletin, local group guide being produced.*
- More focus on watch and wait, keeping well, holistic therapies, complimentary treatments
- Mental health, managing anxiety
- How to tell loved ones
- Promote HU CLLSA Forum resource more.
- Promote CLLSA more

5. “The CLLSA Support Association”: difficulties experienced as members of CLLSA and what CLLSA might do about them

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. Members were pleased the website will be improved, no one mentioned over-informed issue.

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:

- Fatigue and stress management, psychological help and information on mindfulness and relaxation.
- NHS Pathways mapped out and what to seek
- Finding out about Consultant/ Specialist

Concluding comments

Members also were very supportive of the CLL National research findings and recommendations they believed the CLLSA should use to influence strategy and business plans going forward.

Marc Auckland
2nd August 2019

CLL Support Association Conference – Newcastle

Friday 19th July 2019

Life Science Centre Times Square, Newcastle upon Tyne NE1 4EP

See website for details: <https://www.life.org.uk/>

10.00 a.m.	Arrival, refreshments, meet table companions	
10.30 a.m.	Welcome and introduction to the day	Marc Auckland
	Trustee conference host introduces self and agenda	
10.40 a.m.	Members' CLL Stories	
	A personal experience sharing by Bethan. A CLL patient since 2015, Bethan is an active member raising funds, lives in the North East with her family.	Bethan Cawley
	Alice is a retired local government officer, Diagnosed with CLL in November 2018. Alice lives on the East Coast with husband Tony. She is keen to set up a support group in East Yorkshire.	Alice Scanlon
11.10 a.m.	CLL – Patient and Supporter Research	Marc Auckland
	Research was conducted to understand the experiences of people living with CLL throughout the journey, specifically around treatment, relapse and ongoing management of the condition	
11.40 a.m.	Member Round Table Discussion 1 -Member Response	Table Groups
	Does this resonate? Gaps? Priorities?	
12.00 p.m.	Association Update	Marc Auckland
	Trustee briefing on CLLSA progress, highlights, challenges and needs to progress.	
12.15 p. m.	Lunch	
1.15 p.m.	Member Round Table Discussion 2 - Me, My Surgery/Clinic and us	Marc Auckland
	Sharing of personal tips, best practice experienced, where you want us to focus on in the future (Stop/Start/Continue) Also grab a tea/coffee!	Table Groups
2.30 p.m.	CLL - What should I know now that I have it, what treatments are on offer and what might the future hold?	Dr Scott R Marshall MBChB, BSc(Hons), PhD, FRCPATH, FRCP
	Scott qualified as a doctor from Edinburgh University in 1996 and worked in London and the South East before settling in the Northeast. He has always been interested in the immune system, taking a degree in Immunology at Edinburgh and later undertaking a PhD in Immunology and Transplantation at Newcastle University. Scott became a Consultant Haematologist at City Hospitals Sunderland in 2008 and is the lead for the Clinical Trial Research team since his appointment. He also contributes to local laboratory research projects in Newcastle. Scott is also the Clinical Lead for CLL in the Northeast and a member of the UK CLRN CLL Clinical Trials committee. Scott has recruited many patients to clinical trials in CLL and other diseases. He was appointed Clinical Director for Medical Specialities at Sunderland in 2013 and shapes services in the South of Tyne but also continues as a Consultant Haematologist as his main role.	
3.55 p.m.	Conference Wrap up and Close	Marc Auckland

CLL Support Association

Registered Charity No. 1113588

www.cllsupport.org.uk