

# 5 Year Strategy 2020-2025

## **1. Our purpose and aims**

Chronic Lymphocytic Leukaemia Support was set up by, and for, CLL patients.

Our purpose is: -

*‘To inform, support and empower CLL patients in the UK, their supporters, families and friends.’*

We aim to: -

- Provide up to date and accessible information about CLL, encompassing the range of treatments currently available and the latest research into the care and treatment of CLL.
- Develop opportunities to share understanding and personal experience by bringing CLL patients together and creating mutual support groups and networks.
- Act as a voice for CLL patients, representing their interests with the pharmaceutical industry, clinicians, NHS, cancer care policy and drugs regulation authorities, funding and commissioning groups, and politicians.
- Promote awareness of CLL, and the role of the CLL Support, amongst health care providers and decision makers, providers of non-healthcare products and services, other blood cancer patient groups and the wider public.

We are a voluntary organisation, free to all, relying on voluntary donations, gifts and grants.

We are the only organisation wholly devoted to speaking up for CLL patients in the UK – no-one else can.

## **2. A 5-year strategy: - 2020-2025**

To continue to achieve our purpose and deliver our aims while using our resources effectively we need to be clear about our priorities and plans for the future.

This document describes the main things the CLL Support is hoping to achieve over the next 5 years, the broad priorities and the kind of action which will be needed to achieve those things.

It provides a longer-term framework for and clarity about the ‘direction of travel’, which will help to inform our annual plans and budgets, setting out the priorities which those plans will be working towards. It will inform and support our discussions with policy makers, funders, the NHS and health care providers,

pharmaceutical companies, and with our members. Our annual Business plans will set out in detail what we will do over the coming 12 months to deliver our 5-year priorities. It will clearly define what we are aiming to achieve, how we will achieve it, and what it will cost.

### **3. What we have achieved**

CLL Support has made remarkable progress since it was first established by a small group of CLL patients in 2005. Thousands of CLL patients, supporters, family and friends have been able to take advantage of the services we provide.

- Our membership numbers have grown steadily over the years. We now have over 3,000 registered members.
- Our on line forum has grown to over 13,500 worldwide
- Our regular patient member conferences, taking place across the country, have been a valued source of support and information, and a great opportunity to connect and share with others.
- Since it was set up, literally thousands of people have taken the opportunity to access the wealth of information and advice available on our website.
- We have designed and launched a much improved, more user-friendly website
- We have built effective links with clinicians, with cancer care policy groups, with drugs regulation authorities, with research and with the pharmaceutical industry.
- We have been able to provide up to date information about CLL, the treatments available and the latest research.
- We have redesigned our logo, print and digital content to improve our communications; strengthening and clarifying our CLL Support message.
- We have been able to influence developments in CLL research, policy, funding decisions and treatments.
- We have collaborated effectively with other cancer groups and organisations to help represent the interests of CLL patients.
- We have a new patron of CLL Support.
- We have strengthened the Board, increasing the number of serving Trustees, broadening the range of skills and experience and enhancing our capacity and capability.
- We have successfully attracted the funding necessary to do all this.
- We have launched a modern, easy to use new website and reviewed the content
- Launched and grown an under 60's group
- We have above all, given a voice to CLL patients.

### **4. What we could do better**

- There are some 30,000 CLL patients in the UK. Our membership therefore represents just 10%, of CLL patients.
- Awareness of the charity amongst health care professionals is low. While CLL specialists are now well aware of our organisation, our most recent survey shows only 8% of all haematologists and 5% of nurses make patients who join aware of us. They are a key contact with new and existing patients, and well placed to help make their patients aware of the resources we provide.
- Our patient member meetings, provided free to members, are generally fully subscribed and highly valued by those members attending. There are inevitably however limitations in the capacity of venues, the availability, ability and desire of members to attend, and the cost to the CLL Support. The total number attending patient meetings in 2019 was just 502.
- Internet search is the route most new members use to identify the charity. Since March 2015, there have been around 150,000 visits to the new CLL Support website. Allowing for repeat visits, this probably represents about 60,000 patients, family, friends and HCP's. However, even though membership is free, and registration is a relatively simple process, most people visiting the website are not joining the CLL Support which would strengthen our voice lobbying and representing members.
- We believe we should be reaching out and engaging more effectively with the wider CLL community building a stronger sense of community.
- Increase Fundraising with the aim of reducing the percentage total from Pharmaceutical companies.

### **5. Our priorities for 2020-2025 - what we are aiming to achieve over the next 5 years.**

We want to build on our existing strengths and achievements. There are however **a number of key areas which we need to improve on** which we think are critical to achieving our overall purpose of informing, supporting and empowering CLL Support patients in the UK, their supporters, families and friends.

The big areas we need to improve on, our priorities for 2020-2025, are:

First, our four key **'Membership Priorities'** -

- 1) Membership Support and Information
- 2) Membership Engagement
- 3) Membership Advocacy and Awareness
- 4) Membership Growth

We set these out in more detail in the next section (6)

Second, our five key **'Enabling Priorities'** -

- 1) Corporate Funding
- 2) Public Affairs
- 3) Finance
- 4) Information Technology

## 5) Governance

(We set these out in section 7)

## **6 Membership Priorities**

### **6.1 Membership Support and Information**

*We want to continue to improve the quality, range and accessibility of information for CLL patients, their families, friends and Health Care Professionals (HCP's). We want to enable and encourage more local opportunities for accessing information and advice and for connecting with others within the CLL community.*

We will: -

- Develop and distribute relevant, user friendly and readily accessible on line and printed information providing advice for members, local patient support groups, HCP's and clinics. This will include our members booklet, our CLL Support leaflet for clinics, our news bulletins, and supplementary information covering relevant health and well-being issues.
- Regularly update the information, support and advice provided, with an essential core of information available in print as well as on line, including large print and other accessibility provision.
- Deliver 6 Member Conferences a year, offering opportunities for members to share experiences and hear from leading clinicians through high quality conferences. Partner closely with CLL HCP expert speakers to invite attendance through the medical community as well as current advertising.
- We will aim to develop more joint working with sister charities like Leukaemia Care on the content, design and delivery of conferences, events, information and support initiatives.
- Extend the reach and opportunities for access to Members Conferences and other events through the use of on line video conferencing, presentations and interactive workshops and seminars.
- Encourage and facilitate the development of local and on line patient support groups for both members and non-members alike to encourage mutual support. Close collaboration with specialist cancer nurses and clinicians, and with other leukaemia and cancer care organisations, especially Leukaemia Care, will be vital in progressing this.
- Continue the effective administration of the CLL Support Health Unlocked Forum as a trusted, and well-regulated site.
- Continue to offer an effective telephone helpline service for our members. Ensure close collaboration with specialist help lines and resources for specialist needs such as; clinical diagnosis and treatment questions, specialist counselling, and trials information.
- Assess the need for, and in partnership with others, develop and facilitate initiatives to provide emotional support and wellbeing resources to help manage stress and promote living well with CLL.

**2025 Targets: -**

**Member Conferences:**

- 6 a year, total attendance 500 +, participant satisfaction rating of not less than 90%.
- Real time and interactive access to Members Conferences and other events trialed and made available by 2023

**Information for Members:**

- New patient information leaflets to be distributed to all haematology and specialist clinics by June 2020.
- New members' booklet to be available to all members on line, and printed copies to be made available to all specialist clinics by June 2020.
- Six on-line news and information bulletins provide for members each year
- Annual report for members made available from 2020 onwards.
- Further information needs of members to be surveyed and used to develop strategy and service we provide using on line surveys and conference commencing in April 2020

**Support Groups:**

- In collaboration with Leukaemia Care, local clinics, and others identify type, location and number of local blood cancer patient support groups by Jan 2021
- Launch a set up guide and provide promotion of local support groups through the newsletter, website and conferences by August 2020
- Buddy scheme operating well, expanded to include Patients and/or their supporters when requested
- Under 60's WhatsApp support Group thriving and growing Current 57 to grow to 100 by Dec 2020

**Devolved nations of Scotland and Wales:**

- 1 annual conference a year starting by 2021
- 3 local support groups established by end 2020
- Guide on CLL NHS Scotland and Wales pathways developed and made available to members by 2022
- List of CLL members in Scotland and Wales available by end of 2020

**On line support:**

- Provide resources to effectively support Health Unlocked CLL Support Forum
- Real time access and interactive access to Members Conferences and other events trialed and made available by 2023
- Explore and evaluate the scope for provision of on line interactive expert support and advice for Members by 2022

**Help line:**

- All calls logged and monitored.

- Common questions and answers collated to provide a regularly updated FAQ bank by end 2020.
- Follow up calls to check effectiveness of support provided to be in place by end 2020.
- Reports to be provided for board meetings.

**Emotional and psychological support:**

- Expert speakers on emotional well-being at conferences from 2020.
- A standalone emotional well-being session to be created and available for conferences and for local support groups to use by end of 2020.
- Collaboration with sister charities to provide emotional support resources and promote them via the newsletter and website by 2021

**6.2 Membership Engagement**

*We want to enable and encourage wider engagement and dialogue with our members, strengthening the sense of shared support and helping to shape the services provided. We want to encourage, provide and support more opportunities for members, their family, friends and supporters to contribute to, and share in the work of CLL Support as volunteers and Champions.*

We will: -

- Undertake regular surveys of members through the year Inviting feedback and suggestions from members to understand their needs and use to direct strategy and services by end of 2021
- Encourage more volunteers to contribute their time, skills and capabilities to help develop and deliver our services through Champions strategy. This will focus on 3 main areas;
  - awareness raising and provision of information to CLL clinics, CLL healthcare teams, and GP practices with 200 plus clinics and surgeries provides with CLL support Information
  - fundraising initiatives aiming to raise £30,000 a year by 2025
  - support group support and guides to all members wishing to set up or access a group by 2021
- Extend the opportunity for more Members, family, and friends to participate in Members Conferences and other events. This will include;
  - encouraging regional health care professional (HCP) leads to invite their patients to the conferences,
  - extending opportunities for on line and interactive access.

**2025 Targets:**

**Surveys:**

- Identify themes and deliver six annual Surveys via the website that leads into business planning and strategy review by 2021
- Work with other charities and pharma businesses to identify opportunities for survey participation by 2022

**Champions:**

- 70% of Champions engaged in promotion of CLL Support by 2025
- 200 nominated and active Champions supporting us who have access to at least 100 haematology and blood cancer clinics by 2023.

**Fundraising:**

- Increase non pharma fundraising to £60,000 a year by 2025.
- Launch a wills campaign and initial promotion to members and families to encourage legacy gifts to the association aiming for 20 wills by end of 2021.
- Implement a regular donations campaign to encourage members to sign up to a regular donation to the charity. Target 100 by end of 2020. 500 by 2025.

**6.3 Membership Advocacy and Awareness**

*We want to give a voice to our membership, bringing CLL and the experience, the views, and the interests of patients, supporters, family and friends to bear in raising the profile of CLL patients and influencing policy makers, health care providers, the pharmaceutical industry, and the public. We want to raise awareness of CLL Support amongst health care staff, patients, family and friends so that more CLL patients can share in, and have earlier access to, the support we offer.*

We will: -

- Continue to develop our relationships with clinicians, policy makers, and the pharmaceutical industry, to provide a strong voice representing the interests of CLL patients.
- Build on our collaborative work in contributing to the evaluation and assessment of new and developing therapies (HTA) for the treatment of CLL.
- Leverage alliances such as the Blood Cancer Alliance to ensure our patient needs have as high a profile as possible.
- Raise awareness about the Support Association amongst consultants and nurses across haemato-oncology and other specialist clinics, and in GP practices, to ensure that staff and patients are better informed about the support we offer to all CLL patients, their family and friends.
- Campaign for improved psychological support for patients and partners living with CLL.
- Identify opportunities to contribute to the evaluation of new treatment technologies, and ensure that that the experiences, views and needs of CLL patients are effectively represented and voiced to NICE, SMC and other bodies.
- Use agreed key messages driven by the strategy and members views to lobby media, targeted bodies and institution and drive Public relations activities.

**2025 Targets:****HCPs, clinics and GP's:**

- All NHS Clinics and surgeries to be provided with CLL support information. 80% of all clinics and 50% of all GP surgeries by 2023
- Engage with pharmaceutical companies to distribute CLL Support literature and awareness to all the Hospitals they visit and conferences they deliver for Cancer and Haematology HCPs
- Encourage all members and champions to take a CLL Support pack to their local surgery and hospital. Target 50% of champions providing literature to their clinic at least once a year by 2022

**Health Technology assessment:**

- 100 percent response to all HTA involvement requests and submissions by 2021

**Media, public relations and lobbying:**

- Agree the Key messages to be used on every occasion by Feb 2020 (see Public Affairs section 7.2 below)

**6.4 Membership Growth**

*We want to extend our membership so that we represent a larger share of the CLL community and have an even more powerful voice in speaking up for CLL patients in the UK, and their families, friends and supporters.*

Increasing membership offers more people the opportunity of connecting with others in the CLL community, and supporting and engaging with our dedicated CLL Support association and the services we offer. A larger and more representative membership adds to the strength of the CLL Support' s voice, to its credibility and its capacity to influence change for the benefit of all in the CLL community.

We will: -

- Review and improve existing on-line and paper-based approaches to how we promote membership of CLL Support, and new member registration.
- Invite existing members to help support their organization by encouraging new members to join. (Not everyone, of course, who is a CLL patient will want to sign up)
- Ensure every Hospital and surgery has information leaflets
- Work with sister charities to promote awareness of the charities at all conferences, local groups and contacts through sharing and collaborating

**2025 Targets:****Growth:**

- Increase total membership to 6,000 by 2025 (100% increase on 2019 numbers)
- Membership to encompass all genders, ages, ethnic groups profiled in the UK
- Develop and encourage HCP to join. 100 HCPs by 2025

#### **Recruitment**

- Implement initiatives to encourage new members, to make membership registration easier, to convert on line users to registered members.

### **7. Enabling Priorities –**

To enable us to deliver our membership priorities over the next 5 years we have identified five big ‘Enabling Priorities’.

#### **7.1 Corporate Funding**

*We want to make changes to our funding so that we both increase our overall funding in order to deliver our longer-term strategy and effectively rebalance pharmaceutical education grants and other funding. In 2019 after removing an exceptional one-off legacy, the balance was; 51.7% Pharmaceutical grants and 48.3% local fundraising (planned giving, conference donations etc.) Without the pharmaceuticals funding, all given without strings as part of their Corporate Social Responsibility, we simply could not have supported the existing levels of service for our members. At the same time, we believe that we are too dependent on this single source of funding. There is no guarantee that the same level of funding will be available next year or the year after. This represents a risk and challenge for us. While we are careful to ensure any such funding is entirely ethical and without compromise such apparent dependence on the pharmaceutical industry could also put confidence in the independence and integrity of CLL Support at risk. We have now developed and implemented a clear Pharmaceutical relationship strategy which can be found in the Appendix to this document. It builds on the best of charity-pharma relationship research and ensures we have open, clear and managed relationships with all the key pharmas providing CLL drugs, research and treatment that benefit our members.*

We rely in large part on volunteers freely giving of their time to support us. There are nevertheless substantial unavoidable financial costs which require funding to provide services to members and non-members alike. Last year (2018/19) we raised a total of £93,182. Our expenditure was £107,850. This is without the one-off legacy which we are using to fund the new website, brand relaunch, and review, publication and distribution of new materials and support for members.

We will: -

- Grow membership numbers and invite new members to give a (voluntary) subscription on joining
- Encourage regular giving by new and existing members
- Encourage more local fundraising activities
- Seek one off donations from a wider group of corporate and institutional donors

**2025 Targets:**

- Increasing total annual funding, excluding pharmaceuticals, to £100,000 by 2025
- Reducing the proportion of all funding from pharmaceutical companies to 40% by 2025.

**7.2 Public Affairs**

*We want to improve and strengthen our approach to, and capability, in public relations, Lobbying and public affairs.*

To support our strategy of encouraging membership engagement, providing a stronger voice for CLL patients, growing membership numbers, attracting more funding and rebalancing the sources of that funding we need to raise awareness about who we are and what we do. We will focus on delivering and meeting the agreed key Advocacy messages.

We will: -

- Seek opportunities in press and other media to get the CLL key messages across using both in-house resources and a 3<sup>rd</sup> party agency
- Develop and implementing an effective social media strategy for CLL and CLL Support
- Continue to lobby MPs and other decision -makers
- Work with other blood cancer charities to raise profile of blood cancers and ensure a higher focus on research and treatment resources compared to the big 4 cancers.

We have agreed our key Advocacy messages. These are: -

- 1) Establish that, where medically appropriate, targeted drugs and/or combinations of these drugs are accepted treatment for all CLL and SLL patients throughout the UK and to strive for the elimination of chemotherapy.
- 2) Ensure that all patients are fully involved in their treatment decisions.
- 3) Press that all CLL/SLL newly diagnosed patients are seen by, and remain under the care of, a CLL specialist doctor.
- 4) Insist that blood cancer is recognised equally to the four main cancer groups and is given due prominence in allocation of resources.
- 5) Promote CLL/SLL as a major, life threatening, blood cancer and by education aim to eliminate the term 'good cancer'.
- 6) Aim to ensure that all patients are given information about CLL Support at diagnosis. We will achieve this by greater circulation to specialist nurses in particular of our literature.
- 7) Maintain the same benefits of research into, trials of, and access to the latest CLL treatments as the US and Europeans Medicine approvals authorities enjoy.

**2025 Targets: -**

- Key messages in place and all core institutions lobbied regularly to deliver the messages.
- Clear and measurable progress to be achieved in delivering the aims of our agreed key messages.

**7.3 Finance**

*We will ensure the financial management and accounting of the charity, activities and expenditure remains sustainable, aligns to Charity Commission governance and audited every year.*

We will: -

- Provide summary financial reports to members
- Ensure sufficient financial resources and signatories to maintain fiscal operations in case of unforeseen illness
- Manage contractors and staff according to legal requirements and constraints

**2025 Targets:**

- Annual members report published on line
- Annual costed and evaluated business plans available
- Employed and contracted agencies managed to HMRC requirements

**7.4 Information Technology.**

*We want to provide our members with accessible, user friendly, on line information, self-help services and maintain a GDPR compliant database to use for the benefit, and in agreement with members.*

We will: -

- Have in place an effective and user-friendly new website
- Provide on line conference booking, pulse surveys to members and electronic newsletters.
- Ensure that CLL Support uses and embraces social media to maximise our profile and attract new and existing users to our website.
- Have in place robust and fully compliant data protection and security measures.

**2025 Targets:**

- All IT environments are secure, protected and fully supported.

- The website is used effectively and kept up to date, and is the leading CLL information support site for CLL patients, family, friends worldwide by 2025.
- A clear social media policy, strategy and plan in place by 2021
- Data protection and security measures in place and regularly updated to meet legislative and Charity Commission requirements.
- New website and functionality user accessible with member feedback.
- Further developments? E.g. recommended list of apps members can rely on to help manage CLL life etc.; downloadable info packs on CLL and selected aspects such as Keeping Healthy tips...
- On-line self-service donation giving and conference booking
- Electronic newsletter every 2 months

### **7.5 Governance**

*To help make all this happen; we want to improve the effectiveness of the Board and the way the Board works. We want to improve as an organisation and provide support and opportunities for the development of Trustees, Champions and other volunteers.*

Our 2016 review of governance and strategy identified a number of areas for improvement. These included ensuring that our formal charitable constitution complies with best practice; enhancing the Board's resilience; broadening and strengthening the capabilities of the Board; managing the work of the Board better to make use of those capabilities; and developing better planning and budgeting processes.

We will:

- Put in place an effective framework of clearly defined procedures and policies for the operation of the CLL Support, the Board, its sub committees, and individual Trustees.
- Strengthen the Board's capabilities and resilience by appointing new Trustees with relevant skills and experience. (This will increase the overall capacity of the Board, help to reduce the risks of over reliance on any one Trustee's expertise, and hopefully address gaps in existing skills such as fundraising and volunteer development)
- Maintain a Board of 12 Trustees
- Ensure that all Trustees have agreed and clearly defined roles and areas of accountability.
- Enhance the skills, capabilities and effectiveness of the Board by introducing appropriate training, development and appraisal for new and existing Trustees.
- Develop a strategy and annual operational plans and budgets to achieve CLL Support's agreed goals and priorities.
- Create a shared, secure IT library of core documents and calendar for all to draw from and use.
- Expand the number of volunteers to work alongside Trustees, ensuring volunteers are effectively supported by Trustees, have clearly defined roles and appropriate guidance, training and development.

We aim to ensure that we have a capable and committed group of Trustees, Champions and supporters in place who are clear about their roles, are properly supported and developed, and who are working towards agreed and achievable targets within an effective annual planning and progress review framework.

**2025 Targets:**

- Annual business plan to manage progress and activity, shared with members.
- 5 Year strategy reviewed every 2 years, next review in 2022
- Full set of policies to manage the charity, compliant with Charity Commission requirements, available on line available to new and existing trustees by end of 2021
- Trustee and volunteer induction and development programme in place by 2021
- Shared core documents drive including Trustee Calendar available and in use 2021
- Regular charity progress reports shared with members via newsletter and conference

**8. Annual Business Plans**

Each year our annual **business plans** will focus on these agreed strategic priorities, and will set out what we aim to achieve that year, what actions will we take and when, and what resources will be required in order to successfully deliver those **strategic priorities**.

<b>ANNUAL BUSINESS PLANS</b>	<b>Lead Areas</b>												
<b>Targets, Timing, Costs.</b>	Conf'ces	Under 60's	Scotland	Champ's	Help Line	HTA	Comms	Public Affairs	Corp. Funding	IT	Finance	Govern.	
<b>5 YEAR STRATEGY</b>													
<b>Membership Priorities</b>													
<b>Membership Support &amp; Info</b>													
<b>Membership Engagement</b>													
<b>Membership Advocacy &amp; Awareness</b>													
<b>Membership Growth</b>													
<b>Enabling Priorities</b>													
<b>Corporate Funding</b>	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑
<b>Public Affairs</b>	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑
<b>Finance</b>	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑
<b>Information Technology</b>	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑
<b>Governance</b>	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑	↑

## **Pharma Engagement Strategy**

### **Introduction**

In 2025 we want clear pharma relationships, with trustee leads identified, and agreed targets and activities which align to our overall strategy and benefit our members. Progress to be monitored and benefits reported to members.

### **2025 Targets:**

- Pharma strategy embedded, Trustee leads and plans in place. Monitoring via board meetings and annual report to members.
- Clear annual plans and projects agreed and monitored via the Business plan
- Track relationship structure and strategy and ensure it reflects charity-pharma best practice.

The charity's 5-year strategy for 2020-2025 is driven by our core purpose and aims. These include our commitment to: -

- Provide up to date and accessible information about CLL, encompassing the range of treatments currently available and the latest research into the care and treatment of CLL.
- Act as a voice for CLL patients, representing their interests with the pharmaceutical industry, clinicians, NHS, cancer care policy and drugs regulation authorities, funding and commissioning groups, and politicians.

It is our intention to develop a mutually beneficial relationship with the pharmaceutical industry in order to help us deliver those core aims. More specifically, our relationship will be with those key organizations and individuals involved in the research, development, production, and application of new and existing treatments for CLL and related blood cancers for the UK Market.

Developing the right kind of relationships is critical to continuing to improve the support we are able to provide to our members, and the wider CLL and blood cancer community. Those relationships will ensure the charity's voice is heard, position us to influence new drug and treatment developments, provide access to information about new drugs and treatment, and help us access funding and support opportunities across the industry. To ensure our relationships remain even handed, responsible and ethically sound, we will target all five of the pharma businesses currently operating in the UK providing CLL products and services, while also keeping a watching brief on all others and to approach them if they move into the CLL UK market. We will offer the same terms of engagement to all five. We will monitor and review progress, and report to members on any activities we engage in for the benefit of members.

Although we are partially dependent on pharma funding to support our annual operating expenditure, we must maintain an impartial stance in representing our members' needs, and we are taking steps to try to reduce that level of financial reliance. However, we also recognise that working closely with the pharma

companies that research and provide drugs and treatment pathways for our community is key in terms of advocacy for quality of life benefits for CLL/SLL patients and families.

The pharma industry has also clearly begun to recognise the value to them of a new kind of relationship with patients and the charities which represent them. New patient centric approaches, establishing new kinds of partnerships with patients, are being adopted across the industry.

It's in their interest to do this and in our interest to encourage this. The benefits for the industry are clear; improving processes for drug trials and treatment protocols through consultation with patients and patient charities adds value for the industry, it saves time and money, improves treatment effectiveness, and builds trust and confidence in products and brands.

To aid in achieving the relationship building objectives we will, as and when it is deemed appropriate, work in concert with other blood cancer charities.

### **Delivery of the Pharma Engagement Strategy**

Pharma engagement will be led by a team of two Trustees supported by other Trustees as and when required.

The primary responsibilities of the team will be:

- Identifying and establishing contact with relevant pharma company employees
- Preparing annual submissions for grant funding to support the operational, communications and educational costs of the Charity
- Identifying opportunities to engage with the pharma in mutually beneficial projects to improve Quality of Life (QoL) of CLL patients
- Encourage within the pharma companies the development of Patient Centric policies and activities, including the establishment of Patient Advisory Committees (PAC)
- Provide timely updates to the Charity's Board of Trustees

In terms of engagement priority, the pharma companies will be segregated into two groups.

### **Group One – UK Active Companies in the CLL Field**

The majority of our efforts will focus on maintaining long term relationships with the key pharma's active in, or researching on, CLL treatments and drugs in the UK market.

The current group one companies are:

- Abbvie (Venetoclax)

- AstraZeneca (Acalabrutinib)
- Gilead (Idelalisib)
- Janssen (Ibrutinib)
- Roche (Obinutuzumab, Rituximab, Ocrelizumab)

It is our intention that two Trustees will attend the annual EHA conference to monitor any new CLL treatment development and pharma's entering the UK market to ensure they are added to the stream Group One portfolio.

**Group Two – All other companies offering funding.**

The second group would be lighter touch. Less face to face and resource hungry but still making them aware of our work and the ongoing opportunity to donate funds

The current group 2 companies are:

- NAPP (Bendamustine)
- Novartis (Ofatumumab)
- Pfizer
- Sandoz (Rixathon)

The Trustee leads will, at least annually, reach out and contact other pharmas, describing who we are, what we do, and offer to meet to discuss any opportunity to collaborate that will increase the range of available treatments and QoL for our CLL members and community.