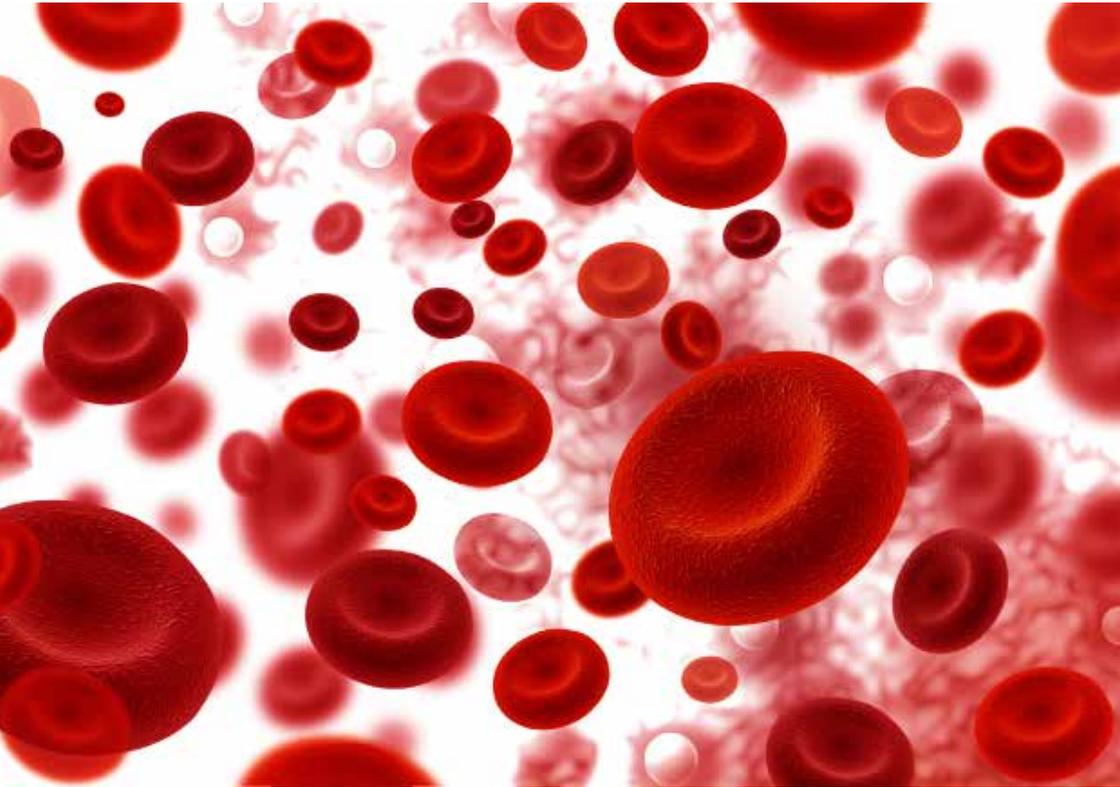

Nursing Matters

Spring 2019

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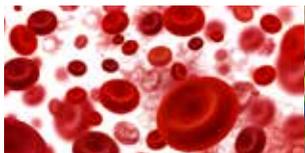
In this edition:

New financial support services for your patients and relaunched nurse bursaries

Leukaemia Care

YOUR Blood Cancer Charity

In this edition



3 BSH updates



5 Leukaemia counselling fund



8 Patient travel fund



10 Nurse bursaries 2019



13 Online e-learning



14 Drug approval updates

Hello and welcome to another edition of Nursing Matters. Can you believe that we're in April already?

Spring has sprung and new ideas and initiatives have been launched by Leukaemia Care. Some of these will be of interest to your patients, such as the Ann Ashley counselling fund and the hospital travel fund. You can find out more about how your patients can access this support on pages 5 and 8.

We've also relaunched our Nurse Bursary scheme and have £20,000 to distribute to nurses applying for courses and training. This scheme is now available throughout the year to ensure you can apply for training without time restrictions. Find out more about the application process on page 10.

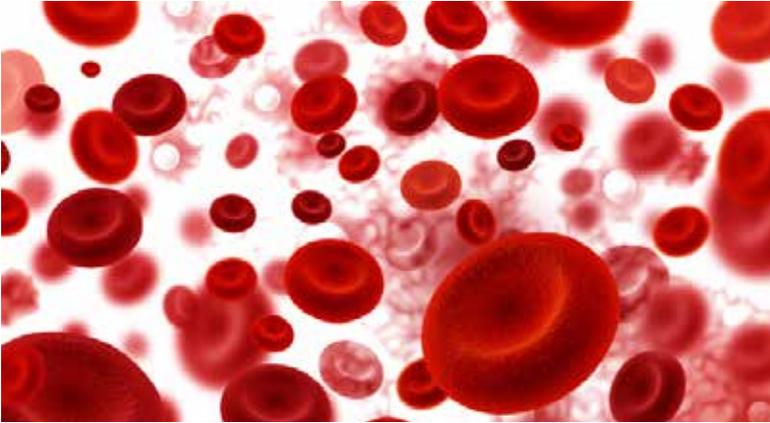
Training is also a hot topic at Leukaemia Care, so we've included information about our upcoming in-person nurse training days as well as the relaunch of our popular online academy.

As always, we love to hear your feedback and we're always here for a chat. You can contact us on support@leukaemiacare.org.uk

Best wishes and until next time,

The Leukaemia Care team

BSH UPDATES



The annual British Society of Haematology meeting took place 1st-3rd April in Glasgow.

Across the three days of the BSH Annual Scientific Meeting, speakers from all sorts of scientific backgrounds discussed a diverse range of exciting haematological topics in over 40 sessions and lectures. The talks ranged anywhere from the latest BSH clinical guidelines, to the importance of nurse research, and the biggest scientific breakthroughs in treatments for haematological disease.

To kick off the conference, The Combined British Society for Haematology and American Society of Hematology hosted a Session entitled "Haematology is central to medicine and global health". This lecture offered invaluable information on how to deal with trauma and haemorrhaging as well as an overview of the genetic nature of blood cancers, and

how this knowledge can be used to accelerate the design of new targeted therapies.

Of-course, it wouldn't be a haematology conference without CAR-T cell therapy getting a mention, as this has been such a hot topic over the past six months. On the Tuesday, Dr Loretta Nastoupil, Dr Sara Ghorashian and Dr Martin Pule hosted an intriguing presentation called "The CAR T-Cell Revolution" focusing on the impact of CAR-T therapy on Leukaemia and how the advances in CAR-T therapy are likely to impact clinical haematology over the next few years.

The final day provided an interesting session unique to this year's conference titled "Behind the Mask: Enduring Pain in Haematology". This will include the stories of patients living with relentless joint pain due to sickle cell disease and haemophilia arthropathy. Visual artist Deborah Padfield presented her work, portraying what it is

BSH UPDATES

quality of life.

Our Patient Advocacy team were also given the opportunity to present the data from our "Living with Leukaemia" survey at this year's conference. Whilst the NHS commissions a survey of the experiences of cancer patients, called the Cancer Patient Experience Survey (CPES), our patients suggest that they face unique challenges. Therefore, our survey, which is the largest ever survey of blood cancer patients, is designed to assess what these differences might be. Presenting the work at BSH will provide scientific validation of the data and allow others to cite it in any further research on quality of life.

The team presented data showing that:

- The symptoms of leukaemia are vague, not well known and rarely associated with cancer, instead often associated with other, unrelated illnesses. Patients delay visiting their GP and then often visit GPs multiple times before referral. Acute leukaemia patients, in particular, have the highest rate of emergency presentation of any cancer, which is linked to worse outcomes for the patient.
- CLL patients placed on "watch and wait" or active monitoring at the point of diagnosis experience a bigger emotional impact than those who started

treatment.

- Acute leukaemia patients face a financial impact, often compounded by both a reduction in income and an increase in costs, as a result of their diagnosis.
- Chronic leukaemia patients are less likely than the average cancer patient to have access to a named CNS. CLL patients on watch and wait are even less likely to have access, despite being shown to have more emotional needs than other blood cancer patients. Having a named CNS has been identified as the single biggest factor that can improve experiences of cancer patients.

The team also presented some recommendations for decision makers and charities alike, which we think would improve the experiences of blood cancer patients. You can read more about our survey on our website at leukaemiacare.org.uk or contact the team at advocacy@leukaemiacare.org.uk for more information. The survey is run annually, so look out for the next opportunity for your patients to get involved.

Launching our new patient fund: The Ann Ashley Leukaemia Counselling fund



Our 2017 patient survey revealed that on average, just 18% of patients are offered counselling services. This is despite 96% of patients wanting information about emotional support that is available.

One of the key recommendations as a result of this survey was that, "More importance needs to be placed on the psychological and emotional needs of leukaemia patients. Signposting to appropriate services should be offered to all patients and should consider those

who may be more 'at risk' from deterioration to their mental health, e.g. due to personal circumstances or treatment path".

This new fund has been named after a former Trustee, Ann Ashley. Ann spent over 30 years volunteering for the charity, offering emotional support to those who had been affected by a leukaemia and was often described as the emotional touchpoint for the charity. She would often counsel those affected by the disease. She died in late

October 2018 and it felt fitting to name the service in her honour.

Your patients could access this support. The criteria are as follows:

What we will fund

- Up to a maximum of six counselling sessions, including the initial assessment.
- Maximum award of £400 per applicant.
- Your patients counsellor must be registered with the British Association of Counselling and Psychotherapy (BACP), or the UK Council of Psychotherapy (UKCP).
- If you require relationship counselling as a result of your leukaemia diagnosis, then counselling through Relate (affiliated through the BACP) is also permitted.
- Counselling can be provided face-to-face, by phone or web cam.
- Counselling will only be provided in the UK.

Eligibility criteria

1. You must be a patient with a diagnosis of leukaemia, or a parent, sibling, child or spouse of a patient.
2. You must be seeking counselling as a direct result of a leukaemia diagnosis either as a patient, or the parent, spouse, child or sibling of a patient.

3. You must be a resident of the UK.

Examples of eligibility

- support for chronic leukaemia patients struggling with being on watch and wait.
- support for leukaemia patients who have relapsed following treatment.
- support for patients with dependent children.
- support for leukaemia patients 100 days post stem cell transplant.
- support for patients struggling with fertility issues as a result of treatment.
- support for patients with a terminal diagnosis.
- support for parents, siblings, children or spouses struggling with bereavement resulting from a leukaemia diagnosis.
- parents, spouses, siblings or children (including young carers) caring for someone with leukaemia struggling with their new responsibilities as carers.

Items not eligible for funding

- Continuation funding for people currently in therapy with a counsellor whether private or NHS.
- Retrospective funding for people who have seen a therapist in the past.

- Counselling provided by a relative or friend, even if they are qualified counsellors.
- Counselling provided by someone who is not registered with either the British Association of Counselling and Psychotherapy, or the UK Council of Psychotherapy.
- Counselling provided by a trainee/student counsellor even if they are registered with either the British Association of Counselling and Psychotherapy, or the UK Council of Psychotherapy.

How your patients can apply

1. The fund opens in April each year. There is no closing date, awards are distributed on a first come, first served basis until the fund is depleted for the year.
2. Applications can be found on the Leukaemia Care website or you can request a copy of the application form by ringing 08088 010 444 or email nurse@leukaemiacare.org.uk
3. Your patient will need to enclose a copy of a letter from their consultant confirming their diagnosis – scan and/or photocopies are acceptable.
4. If you have any queries about the fund or how to complete the application form, please call the Leukaemia Care helpline on 08088 010 444 and ask to speak with Fiona Heath.

Processing their application

- We will acknowledge receipt of your patients application.
- Your patients application will be assessed by the Patient Advocacy team.
- Your patient can expect a decision within 10 working days of Leukaemia Care assessing your application.
- All applicants will be informed of the outcome of their application by email or post.
- Successful applicants will also be contacted by phone to discuss next steps.

Terms and conditions

Your patients application will only be assessed if

- Your patient meets all of the eligibility criteria.
- all parts of the application form are fully completed.
- there are funds remaining within the counselling fund for distribution.

Hospital travel fund for those affected by leukaemia



One of the most important areas for leukaemia patients is the impact of cancer on their finances. On average, 43% of people reported experiencing a negative impact on their finances, and this ranges between 36% and 56% across the different leukaemia types.

Leukaemia Care is looking to alleviate some of these ongoing costs for patients and the hospital travel fund has been devised to address this.

The Leukaemia Care Hospital Travel Fund

Leukaemia Care are offering grants of £200 towards the cost of travel to hospital for patients and families affected by leukaemia.

What we will fund

- maximum award of £200.
- grants cannot be applied for retrospectively. This fund is available for leukaemia patients that are currently undergoing treatment, chronic lymphocytic leukaemia (CLL) patients on 'watch and wait' or chronic myeloid leukaemia (CML) patients in the first year of treatment-free remission (TFR).
- grant can be used towards bus tickets, train tickets, fuel, car maintenance, parking and taxi fares.
- one grant per family.

Eligibility Criteria

The applicant must be a patient with a diagnosis of leukaemia, or a parent, sibling, child or spouse of a patient.

- The applicant must be seeking funding for travelling to/from hospital.
- The applicant must be a resident of the UK.

How your patients can apply

1. The fund opens in April each year. There is no closing date, awards are distributed on a first come, first served basis until the fund is depleted for the year.

2. Please complete the application form which can be found on the Leukaemia Care website. Alternatively, forms can be requested by ringing Leukaemia Care on 01905 755977 or email support@leukaemiacare.org.uk

3. Please enclose a copy of a letter from your consultant confirming your diagnosis – scan and/or photocopies are acceptable.

4. If you have any queries about the fund or how to complete the application form, please call the Leukaemia Care helpline on 08088 010 444 and ask to speak with Fiona Heath.

Processing your patients application

- We will acknowledge receipt of their application.
- Their application will be assessed by the Patient Advocacy team.
- They can expect a decision within 10 working days of Leukaemia Care assessing your application.
- All applicants will be informed of the outcome of their application by email or post.

Successful applicants will also be contacted by phone to discuss next steps

Terms and conditions

Your application will only be assessed if

- your patient meets all of the eligibility criteria.
- all parts of the application form are fully completed.
- there are funds remaining within the counselling fund for distribution.



Nurse bursaries 2019

Our Nurse Bursary scheme is now open all year round.

Leukaemia Care is committed to enhancing patient care through supporting nurses caring for blood cancer patients by providing bursaries towards

- learning and development activities such as post-graduate university study or professional short courses.
- attending relevant conferences and seminars, including Leukaemia Care nurse conferences.

We have **£20,000** available for Nurse bursaries from April 2019 - March 2020.

Items eligible for funding

- Fees for relevant post-graduate courses or professional short courses.
- Delegate fees for relevant conferences and seminars e.g. British Society of Haematology, EBMT etc.
- Travel costs for relevant conferences and seminars but not taxis or mileage.
- Accommodation costs, e.g. for attending conferences.
- Child care costs where these are additional costs incurred while undertaking learning

and development activities.

Items not eligible for funding

- Membership fees for professional bodies.
- Books.
- IT equipment or software.
- Meals and subsistence.
- Taxis or car mileage, unless there is a medical or other compelling reason.

Eligibility criteria

1. You must be a nurse currently registered in the UK.
2. You must be working predominantly with blood cancer patients either adults or children.
3. Previous recipients of a Leukaemia Care bursary (including those awarded under our previous partnership with the RCN Foundation) are eligible to apply only if they have fulfilled all the terms of their previous bursaries and submitted their reports in a timely manner.
4. First time applicants may be given priority.
5. Student nurses are not eligible to apply to this scheme.
6. Your course of study must start within one year of being awarded

a bursary.

Amount available

Bursaries of up to £2,500 are available and are paid directly to the training or conference provider on receipt of an invoice. Travel costs will be reimbursed on production of receipt.

How to apply

1. The scheme opens in April each year. There is no closing date, bursaries are awarded on a first come, first served basis until the fund is depleted for the year.
2. Please complete the application form below and return to nurse@leukaemiacare.org.uk or via post to FREEPOST RLXX-RJRA-ACRH, Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG. We have included an application form with this edition of the magazine. If you require further forms, they can be downloaded from the Leukaemia Care website. Alternatively, you can ring 01905 755977 and request a form or email nurse@leukaemiacare.org.uk.
3. If you have any queries about the bursary or how to complete the application form, please call the office on 01905 755977 and ask to speak with Fiona Heath.

Processing your application

- All applicants will have their application acknowledged.
- Bursary applications will be assessed on the 22 May, 24 July, 25 September and 27 November 2019.
- Applications must be received at least five working days before the assessment date, or they will be considered in the next cycle.
- You can expect a decision within five working days of Leukaemia Care assessing your application on the dates above.
- All applicants will be informed of the outcome of their application by email or post.
- Successful applicants will also be contacted by phone to discuss next steps.

Terms and conditions

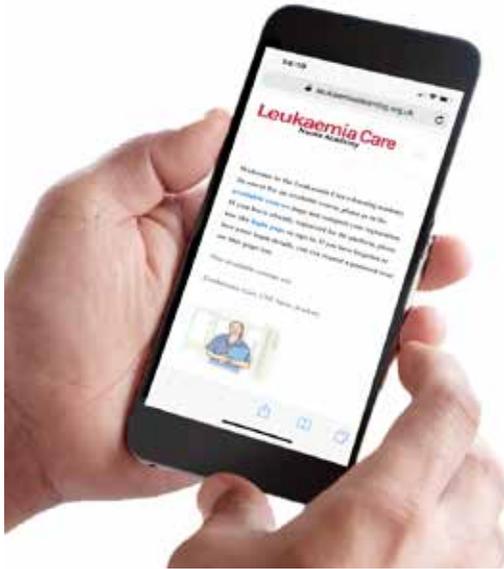
Your application will only be assessed if

- you meet all of the eligibility criteria.
- all parts of the application form are fully completed.
- there are funds remaining within the bursary scheme for distribution.

Leukaemia Care publications available for order:

A-Z of Leukaemia
AMKL
Acute Myeloid Leukaemia
All About Leukaemia: An Easy Read Document
Allogeneic Stem Cell Transplants
AMKL
Autologous Stem Cell Transplants
Acute Lymphoblastic Leukaemia
Acute Promyelocytic Leukaemia
Aplastic Anaemia
ATRA and anthracycline based therapy for AML
Azacitidine for AML
Caring for carers
Childhood Acute Lymphoblastic Leukaemia
Childhood Acute Myeloid Leukaemia
Chronic Lymphocytic Leukaemia
Chronic Myeloid Leukaemia
CML, TKI's and TFR
Chronic Myelomonocytic Leukaemia
DA and ARAc for AML
Essential Thrombocythaemia
FLAG-Ida for AML
Hairy Cell Leukaemia
Hydroxycarbamide for AML
JMML
Late Effects of Treatment
Living well with AML
Low dose Cytarabine for AML
Mylotarg for AML
Myelodysplastic Syndromes
Myelofibrosis
Polycythaemia Vera
Relapse in AML
Relapse in CML
Relapse in ALL
The next stage
Treatment for APL
Watch and Wait

To order free patient information for your department, email support@leukaemiacare.org.uk, head to the website at www.leukaemiacare.org.uk/support-and-information/help-and-resources/request-a-resource/ or ring 01905 755977.



The Leukaemia Care nurse academy

Our e-learning platform has been relaunched, making it easier for you to access your 10 hours of accredited CPD.

Have you accessed the Nurse Academy yet?

The Nurse Academy has now moved to the following website:

leukaemiaelearning.org.uk

Following feedback from nurses, we have looked to enhance the platform. These enhancements include:

- Accessing course workbooks for each chapter of the course.
- The ability to complete the course from a mobile phone.

- Certificates emailed to you following completion of each section.
- Ability to self-register for the course.

For support in registering for the course, please email support@leukaemiacare.org.uk.

Drug approval news

Arsenic trioxide for APL in Scotland

The Scottish Medicines Consortium (SMC) have announced that arsenic trioxide is not recommended for NHS patients in Scotland. Find out more about this decision and how it affects acute promyelocytic leukaemia (APL) patients.



The Scottish Medicine Consortium (SMC) have today announced that arsenic trioxide is not recommended for NHS patients in Scotland. The brand name for this drug is Trisenox and it is manufactured by Teva. Teva are

resubmitting with further evidence in response to this decision.

Arsenic trioxide was appraised by the SMC for treating acute promyelocytic leukaemia (APL). APL is a rare form of acute myeloid

Keep up with the latest news and patient stories at www.leukaemiacare.org.uk

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Many thanks to these following people and for their contributions:

Nicole Scully, Monica Izmajlowicz, Fiona Heath, Fergus Metcalfe, Charlotte Martin

leukaemia. In APL there is a genetic abnormality called a translocation which usually leads to the creation of a faulty gene called PML/RAR-alpha. It was considered for use in newly diagnosed, low to intermediate risk APL patients when combined with all-trans-retinoic acid (ATRA).

The Scottish Medicines Consortium (SMC) is responsible for appraising technologies for use within NHS Scotland. The SMC undertakes assessments to review the value of each new medicine and to determine the benefits and costs. The Scottish Medicine Consortium (SMC) announcement states that the manufacturer, Teva, did not submit a "sufficiently robust" economic analysis to allow the SMC to make a recommendation. Teva are resubmitting with further evidence in response to this decision.

Arsenic trioxide is a medicine that acts to slow or stop the growth of the cancer cells. It has been used for a number of years to treat leukaemia. Whilst toxicity of arsenic is well recognised, alternative treatments for APL also come with significant side effects. Arsenic trioxide has been investigated in clinical trials against the standard treatments (anthracycline chemotherapy). The trials included patients that were newly diagnosed and low to intermediate risk. Risk

is defined by the number of white blood cells in the patient's blood at diagnosis; more white blood cells indicates that disease has progressed already, which may be harder to treat and is therefore higher risk. The trial did show that arsenic is as good as anthracycline chemotherapy (a common first line treatment) in terms of event-free survival. Arsenic trioxide was superior to anthracycline chemotherapy in terms of overall survival too.

"We are disappointed with the SMC's decision not to allow individuals diagnosed with acute promyelocytic leukaemia access to arsenic trioxide," said Zack Pemberton-Whiteley, Patient Advocacy Director at Leukaemia Care. The manufacturer Teva have resubmitted to the Scottish Medicines Consortium with further evidence for assessment. We will continue to work with the SMC to ensure patients are given access in the future.

Drug approval news

NICE approves venetoclax (VENCLYXTO) with rituximab for previously treated chronic lymphocytic leukaemia (CLL) patients

NHS England are to make the first targeted CLL chemotherapy-free combination treatment of a fixed duration available through routine commissioning to treat patients relapsing or failing a first treatment.

The National Institute for Health and Care Excellence (NICE) published the Final Appraisal Document (FAD) approving the use of venetoclax with rituximab to treat relapsed and refractory chronic lymphocytic leukaemia (CLL) patients in England. They concluded that venetoclax plus rituximab is a cost-effective use of NHS resources and is recommended for routine commissioning.

NICE recommendation states:

"Venetoclax with rituximab is recommended, within its marketing authorisation, as an option for treating chronic lymphocytic leukaemia in adults who have had at least one previous therapy".

Venetoclax otherwise known as Venclyxto, is produced by AbbVie. Rituximab was originally produced

by Roche and is now also available to NHS in a biosimilar form from other manufacturers. Both are types of targeted drugs.

Venetoclax is an oral BCL-2 inhibitor. The BCL-2 cellular protein prevents apoptosis (programmed cell death) causing CLL cells to accumulate. This medicine restores the death instinct in the CLL cells. Rituximab is a monoclonal antibody, rituximab targets a protein called CD20 on the surface of the leukaemia cells. The antibody sticks to the CD20 proteins it finds, then the cells of the immune system pick out the marked cells and kill them.

Venetoclax was also approved in 2017 by NICE for use as a single agent to treat CLL patients with a 17p deletion or TP53 mutation and if unsuitable for, or if relapsed from a B-cell receptor (BCR) pathway inhibitor treatment.

Venetoclax as a single agent was also approved in 2017 to treat CLL patients without a 17p deletion or TP53 mutation in the relapsed setting, but only patients relapsing from two lines of previous therapy, both a chemo-immunotherapy and BCR inhibitor.

Alternative options for treating second line CLL patients today typically involve continuous treatment with the targeted non-chemotherapy drug ibrutinib. For patients seeking a treatment free period, retreatment with a chemo-immunotherapy is the only option, which is often unsuitable. Today's decision by NICE is a significant change in CLL treatment and how it may be managed into the future. Patients who have received at least one prior therapy, now have NHS access through routine commissioning to a chemotherapy-free targeted combination treatment. The treatment is for a fixed term of 24 months and offers potential for a treatment free period.

The NICE recommendation to make venetoclax plus rituximab available was based upon MURANO Phase 3 clinical trial data. The trial compared venetoclax plus rituximab treated patients to bendamustine plus rituximab treated patients. The primary outcome measure in MURANO was progression-free survival (PFS). At the time of the analysis, the trial demonstrated an eighty-three percent reduction

in the risk of disease progression or a prolonged overall survival (OS) compared to the standard of care. At 36 months 60% of venetoclax plus rituximab patients in the trial had undetectable minimal residual disease, which is a strong predictor of lasting remission in patients with chronic lymphocytic leukaemia.

Nick York, a chronic lymphocytic leukaemia patient working at Leukaemia Care commented:

"Leukaemia Care welcome NICE's decision to make this important treatment available to patients relapsing or failing after first treatment. This is a major step change for CLL treatment and has the potential to transform how the disease is managed and treated. Patients worry of relapse and what may come next. Access to a chemotherapy-free option which offers the potential of a treatment break, will uplift the community and improve patients' quality of life".

Drug approval news

Scottish Medicines Consortium approves Kymriah to be funded for use on the NHS in Scotland

Kymriah is a brand of CAR-T therapy, a pioneering new treatment for blood cancer patients. Find out more about the approval, and who it will benefit, here:

The Scottish Medicines Consortium (SMC) has approved the use of Tisagenlecleucel-T (brand name Kymriah) to be funded for use on the NHS in Scotland. It will be available for B-cell acute lymphoblastic leukaemia (B-ALL) patients aged 25 or less, who have refractory disease or have relapsed following a transplant or two or more other therapies. Kymriah is a brand of chimeric antigen receptor (CAR) T-cell therapy. It is manufactured by Novartis and was the first CAR-T therapy to be approved in the UK when it was approved for use in England in November 2018.

CAR-T therapy, also called adoptive T cell therapy, is a type of immunotherapy, meaning parts of the immune system are used as a treatment. Immunotherapy usually uses parts of the immune system made in other animals or in a laboratory, such as antibodies. CAR-T cell therapy is brand new and innovative, involving the harvesting

of patient's own immune cells from their body to be used in the treatment. The cells are taken from the body, edited to be more effective at fighting the cancerous cells, then returned to the patient's blood to start fighting the cells. The process tailors the treatment to each patient and therefore the cost can be high.

ALL is a type of leukaemia that affects your lymphocytes, which is the collective name for the blood cells called B and T cells. These cells go through many stages of development before they become cells that can work properly in your immune system. ALL happens because the cells have not developed properly, so your bone marrow and blood fills with immature cells that cannot protect you. ALL can affect either B or T cells, but B-ALL is more common in adults. CAR-T cell therapy, as mentioned above, requires working T cells from the patient's body, which is why it has been approved

for B-ALL patients only (i.e. only their B cells are developing incorrectly).

There can be some severe side effects, but the treatment is approved here for use where B-ALL patients have tried other therapies, which may have less severe side effects, but they have not worked. Despite the severe side effects, the SMC approved Kymriah due to the high success rate of the treatment. In the clinical trial data that was submitted to the SMC, 81% of B-ALL patients achieved remission of their disease three months after treatment with Kymriah.

At the time of approval in England, the Head of NHS England described Kymriah as a "true game changer". Our Patient Advocacy Director, Zack Pemberton-Whiteley, said of today's SMC decision: "CAR-T therapy is promising, with curative potential for acute lymphoblastic leukaemia patients who have exhausted most alternative treatments. We are glad that SMC has chosen to fund Kymriah so patients are able to access this important new treatment as soon as possible and wherever they live in the UK".

Leukaemia Care patient conferences - now taking bookings

Our patient conferences have been announced for 2019/20.

The information days are open to patients, their loved ones and health care professionals. These events are free of charge to attend.

This year, these events will cover the topics of fatigue, diet and nutrition, exercise and emotional support.

The dates for the year are as follows:

1st June - Sheffield
15th June - Exeter
27th July - Cambridge
14th September - London
12th October - Cardiff
16th November - Birmingham
7th March 2020 - Glasgow

If you or one of your patients are interested in attending, you can confirm your free place by:

- Ring the Patient Advocacy team on 01905 755977
- Email the Patient Advocacy team Support@leukaemiacare.org.uk
- Book at: www.leukaemiacare.org.uk

Drug approval news

Liposomal cytarabine with daunorubicin approved for use in Scotland for t-AML and AML-MRC

The Scottish Medicines Consortium (SMC) has recommended the use of liposomal cytarabine with daunorubicin to treat previously untreated therapy-related AML (t-AML) and AML with myelodysplastic -related changes (AML-MRC).

This follows the recent news that the National Institute for Health and Care Excellence (NICE) have also recommended that this drug be used on the NHS in England. The brand name for this treatment is Vyxeos and it is manufactured by Jazz Pharmaceuticals.

Liposomal cytarabine is a chemotherapy drug which works by imitating a part of DNA called cytidine. Cells replace the cytidine with the drug cytarabine in their DNA. The presence of cytarabine in place of cytidine then stops the cell from being able to replicate the DNA and causes the cell to die. Cytarabine is already used to treat acute myeloid leukaemia (AML), but Vyxeos is different in that the cytarabine is encased in droplets of fat molecules called liposomes. It is thought that doing this may make the cytarabine work better and last longer in the body, hence why it is

has been proposed as an alternative treatment to standard cytarabine.

Both kinds of cytarabine are delivered with daunorubicin, which also works by preventing DNA from replicating, but it does this in a different way to cytarabine. It is called an intercalator, meaning it sits in gaps in the DNA, stopping enzymes in the cell from copying or fixing the DNA. Again, this leads to the death of the cells. It is targeted at the leukaemia cells by being delivered into the bloodstream. AML patients undergo several stages of the chemotherapy to induce and sustain remission; the SMC has approved liposomal cytarabine and daunorubicin for both induction (the first stage) and consolidation (subsequent stages) chemotherapy.

The decision was made following a clinical trial called Study 301, which was run in the USA and Canada.

The trial was conducted in adults aged between 60 and 75 years who had "high-risk" AML which had not yet been treated. High-risk AML included patients who had AML as a result of treatment for other cancers (known as therapy-related AML, t-AML) or AML with myelodysplastic-related changes (AML-MRC). These types of AML can be difficult to treat; for example, therapy-related AML has arisen as a result of other chemotherapy, so one must choose chemotherapy options to which the leukaemia cells will not already be resistant. Patients receiving liposomal cytarabine with daunorubicin had an increased overall survival time of nine months versus just under six months for the comparison group of patients, who were receiving non-liposomal cytarabine with daunorubicin.

SMC have concluded that this medicine is cost-effective for use on the NHS in Scotland, in addition to the evidence presented showing that the treatment works.

"Gaining access to any new treatment that has the potential to increase survival is great news for patients with high-risk AML, said Zack Pemberton-Whiteley, our Patient Advocacy Director. The SMC's announcement is a really positive development for t-AML or AML-MRC patients in Scotland, helping families gain more precious time with their loved ones".

Leukaemia Care launch brand new podcast, "Bloodstream"



This is another new service for 2019 and we'd love you to get involved.

Bloodstream has been launched for patients, carers and healthcare professionals and is a podcast that talks about various aspects of living with leukaemia - from nutrition to patient stories.

Please share this information with your patients and listen yourself. You can find Bloodstream by Leukaemia Care on most podcast providers and platforms or you can listen via the Leukaemia Care website.

If you would be interested in being a future guest on the podcast, please email communications@leukaemiacare.org.uk

Drug approval news

Scottish Medicines Consortium has not approved the use of Tisagenlecleucel-T for diffuse large-B cell lymphoma (DLBCL)

The Scottish Medicines Consortium (SMC) has not approved the use of Tisagenlecleucel-T (brand name Kymriah) on the NHS in Scotland for patients with diffuse large-B cell lymphoma (DLBCL). Kymriah is a brand of chimeric antigen receptor (CAR) T-cell therapy and is manufactured by Novartis.

Specifically, the therapy was being evaluated for use in relapsed or refractory adult patients who have tried two or more other therapies. This is the second type of CAR-T therapy that has failed to be approved by the SMC for DLBCL. The first was axicabtagene ciloleucel (brand name Yescarta, manufactured by Kite). However, the SMC has previously approved the use of Kymriah for patients with acute lymphoblastic leukaemia (ALL).

CAR-T therapies are currently only considered in relapsed patients who have tried other therapies as the way it works can also cause some severe side effects. CAR-T therapy, also called adoptive T-cell therapy, is a type of immunotherapy, meaning parts of the immune system are used

as a treatment. Immunotherapy usually uses parts of the immune system made in other animals or in a laboratory, such as antibodies. CAR-T cell therapy is brand new and innovative, involving the harvesting of a patient's own immune cells from their body to be used in the treatment. The cells are taken from the body, then edited to be more effective at fighting the cancerous cells, then returned to the patient's blood to start fighting the cells. The severe side effects can arise when the T-cells are returned to the patient and they kill so effectively that they can also harm the rest of the body. This is similar to the reason why flu feels so awful; when your immune system is trying to fight something, sometimes it fights so hard that it makes you feel awful (in the case of the flu, it is not the virus itself that causes many of

the symptoms but this very strong reaction by the immune system). The process of CAR-T therapy tailors the treatment to each patient and, therefore, the costs can be high.

The SMC indicated that the company, Novartis, did not present enough evidence to show that the benefits gained by patients were enough to offset this high cost to the NHS, and that this was the basis for their decision. The company now have the opportunity to re-submit with further evidence, although this causes a delay in access while this process is completed.

This decision creates a situation where access to CAR-T therapy varies across the UK for DLBCL patients, as NICE has approved both Kymriah and Yescarta for DLBCL patients in England, whereas Scottish patients have no access to either brand of CAR-T therapy currently. It also creates inequity of access to the same type of treatment for patients with different blood cancers, due to SMC approving Kymriah for use in patients with ALL, as mentioned above.

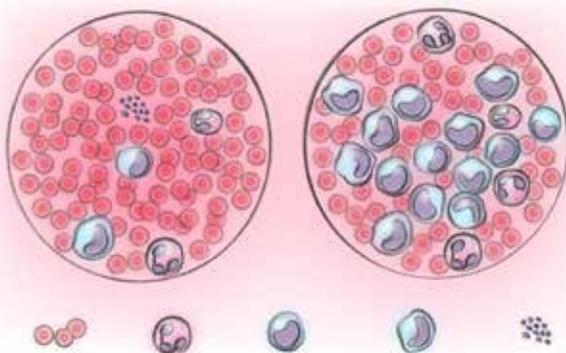
At the time of approval in England, the head of NHS England described Kymriah as a "true game changer". Our Patient Advocacy Director, Zack Pemberton-Whiteley, said of today's SMC decision: "CAR-T therapy is promising for patients who have exhausted most alternative

treatments. We are disappointed that the SMC has chosen to not fund Kymriah, despite having chosen to fund it for patients with other conditions and funding being available in England, so all patients are able to access this important new treatment as soon as possible and wherever they live in the UK."

**For regular updates
on topics such as drug
approvals, please see the
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Venues and speakers to be confirmed. Please register your interest to receive updates on agendas and locations. Future agendas will also be published in Nursing Matters magazine.

RCN Accreditation to be confirmed. Places will cost £45 each and nurses can apply to the Leukaemia Care bursary scheme for financial assistance in attending one of these days.