

WHAT WE HAVE FOR YOU IN THIS ISSUE

From chatting with Dr. Bate, to sharing the symptoms for Acute Myeloid Leukemia (AML) as we approach AML Awareness Day, and much more, we have everything you need to keep up to date in this first edition.

AML World Awareness Day

21ST APRIL 2022
#BeLeukemiaAware

April 21st is AML World Awareness Day. While it is important to recognise the symptoms and signs of the disease 24/7, for our community, it is important that we capitalise on these global days when we bring the community together and encourage those who are not so 'clued' up to learn the signs and symptoms about (acute) leukemia.

AML is one of the more aggressive forms of blood cancer, the treatment can be fast and harsh and often leaves patients in hospital for long periods of time. The work that the advocacy community, including ALAN does, ensures that those effected by this disease are as comfortable and considered as possible.

Due to AML's fast progression, and leukemia in general, it is vital that we are aware and continue to spread the awareness of signs and symptoms to the wider audience. Due to the fact that symptoms are usually quite vague and general, it is very rare that a patient suspects leukemia before going to their doctor and getting checked.

With this in mind, we would love to encourage you to raise the word to others and use the hashtag **#BeLeukemiaAware** across all social platforms.

On 21st April, for AML World Awareness Day, we will be running a variety of activities across ALAN social media platforms. We will encourage AML patients (or anyone who had been close to AML) to share symptoms, stories, motivational quotes that helped during the journey. We also have Rian, one of our team members who has been through AML twice in his teenage years to answer questions.

Awareness days are important in the calendars. It is always great to see so many share their knowledge or experiences. We look forward to seeing some of yours.



Q&A with Dr. Bate



MEET DR. BATE

Dr Jessica Bate is a member of the pediatric oncology team at Southampton General Hospital, UK.

Dr Bate is a Consultant Paediatric Oncologist at Southampton Children's Hospital, UK and takes care of many children with solid tumours and leukaemia.

We sat down with doctor Bate to talk about acute leukemia, especially AML.

With AML awareness day this month, what is the biggest misconception you find about this disease?

AML is more common in people over 60 but children and young people can also develop AML. Approximately 3,000 adults in the UK are diagnosed with AML each year but only around 100 UK children and young adults under 19 years old are diagnosed with AML. Although it is primarily a disease that affects adults, it is important not to forget that children and young people can have AML too.

The advancement in treatment recently is immense. What do you think the future has in hold for us?

It has been very exciting to have an international clinical trial for children and young people with AML called Myechild where a drug called gemtuzumab is being used with chemotherapy. Gemtuzumab is a monoclonal antibody which is a type of targeted drug therapy.

The Myechild trial is also investigating different combination of chemotherapy drugs for induction chemotherapy and their side effects. It also wants to answer whether different combination of chemotherapy drugs such as consolidation treatment work better than standard treatment to stop leukaemia coming back.

Reducing long-term chemotherapy side-effects such as damage to the heart by using different drugs is another important aim of the study.

Some children and young people with AML who are identified as having a higher chance of the leukemia returning are recommended to receive a stem cell transplant. The chemotherapy before a stem cell transplant is called conditioning treatment. The standard is myeloablative conditioning (MAC) which works well but has many side effects. The Myechild trial wants to find out whether using reduced intensity conditioning (RIC) is as good as MAC and whether RIC has fewer side effects.

The advancement in AML treatment now includes detailed methods to stratify patients by cytogenetic (these tests look for chromosome (genetic) changes inside the leukemia cells) and molecular characteristics and the response to the first course of induction chemotherapy assessed by morphology and minimal residual disease (MRD) measurement. The MRD test is one of the biggest cancer breakthroughs of the last 30 years. The MRD test helps determine how much treatment a child or young person will need. The future of AML treatment in young people will be based on the results from the Myechild trial.

Q&A with Dr. Bate

What is the most common ignore symptom, or missed symptom you tend to see as a consultant?

For children and young people, the most common symptoms of acute leukemia are feeling tired, pale skin, repeated infections over a short period of time and unexplained bruising and/or bleeding. Most of these symptoms are caused by a lack of healthy blood cells.

Other symptoms than can also indicate leukemia include pain in the bones or joints or a limp.

Occasionally, leukemia cells can spread from the blood to the central nervous system and cause symptoms such as headaches, dizziness, blurred vision, vomiting or seizures.

What is your advice to someone who is advocating for leukemia, what would you say is the most important voice that needs to be raised?

The voice of parents or carers with experience of childhood leukemia and survivors of leukemia needs to be louder to influence research.

Patient and Public Involvement and Engagement (PPIE) offers researchers valuable and unique insight into the particular condition being investigated to make research more relevant to patients. It is needed to improve the quality of research and to focus the questions being asked.

You can make a difference at any and every stage of research. Your voice can influence people beyond the research team, including those who take part in the research and people who use the results. There are many different ways in which those advocating for leukemia can get involved in research including defining the research questions, planning and designing the research, developing documents for research participants, contributing to the monitoring of the research and the sharing of results.

Dr. Bate, thank you for taking time out of your already busy schedule to speak with us and help raise the voice of leukemia within the community. Your words really resonate with us and we know that the readers will hopefully take some bits from this too!

REFERENCES

The references below are supplied by Dr. Bate with no influence from ALAN.

- Children's Cancer and Leukaemia Group (CCLG)
- Cancer Research UK
- Blood Cancer UK
- Macmillan Cancer Support
- National Institute for Health Research

WHO DO YOU WANT TO HEAR FROM?

We are always looking to expand the growing network we have here at ALAN and so we want to know who do YOU want to hear from in the next issue? For suggestions please email: rian@acuteleuk.org

FOR MORE VISIT: <https://acuteleuk.org/>

UPDATES FROM ALAN

GET INVOLVED

We are all knowledgeable of the research and work that goes into developing and bettering cancer care and treatment. We believe that those of you who have lived experience should be kept at the heart of development. No one knows the world leukemia creates better than those who have lived it. This may be you or people within your organisation ?

Shortly together with our colleagues from CML AN and CLLAN, we will be launching our Carer Experience Survey ! And we want to ensure all voices are heard on matters such as diagnosis, care, treatment and more for leukemia.

Keep an eye on our social platforms and website for a launch during this quarter !

FOLLOW US !

As we touched on at the beginning of the newsletter , April 21st is AML Awareness Day.

To ensure we are able to reach as many people as possible we will be using our social media platforms to encourage people to ask questions, share stories and engage in some of the content we will be sharing.

Feel free to check into our socials, follow us and get involved.

Facebook: @ALANacuteleuk

Instagram: @alan_acuteleuk

LinkedIn:@acute-leukemia-advocates-network

Twitter: @AcuteLeuk

UPCOMING WEBINARS

This year again we continue our online events. We will be bringing you a webinar every month, each one covering a fresh and new topic.

Here is the ones coming up this quarter:

APRIL - Treating leukemia in low and medium income countries.

MAY - Biosimilars and generics

JUNE - CAR-T therapy, the run down

If you are interested in attending any of these please keep an eye on our website and Facebook page where we will be announcing them.

JOIN ALAN

As we continue to expand the global connections, we would like to show you more ways you are able to join the team and advocate for the cause along side us. It is clear that more needs to be done for acute leukemia, and you can help us do that. Find out more by visiting our website. It is time to leave a mark on this planet, to ensure the lives of others are positively impacted by that.

FOR MORE VISIT: <https://acuteleuk.org/>



COUNTDOWN TO WLD

#BeLeukemiaAware

With six months to go until World Leukemia Day on 4th of September, we are beginning planning to ensure we reach as many people as possible to push the messages surrounding the signs and symptoms of leukemia.

Together we are more powerful than alone. We would love to have you involved in this years campaign. A community is louder than an individual.

In upcoming newsletters as we move even closer to this special day in our calendar we will be updating you on ways you can aid the voice.

ACUTE LEUKEMIA GLOBAL SUMMIT

We pride ourselves on connection, seeing it as a vital part of what we can call do as a community to raise the voice and change the perceptions of acute leukemia. An important part of that is to ensure we are able to meet and understand as many peoples needs as possible.

This year we will be returning with our global summit. We are still monitoring the developing covid19 situation and whilst every effort is being made to offer an in-person option it is likely this will once more be a virtual event.

We will keep you updated closely and we hope to see you there, either virtually or in person.

WHAT CAN YOU DO?

We often get asked if there us anything you as a follower can do to help the cause we advocate for so loudly.

There is indeed something you can do.

If you have enjoyed the content you have read within this edition then please do share to colleagues, friends and family to encourage them to learn more on this topic.

Without you there is no cure, and that runs true with the power to share information to educate and change many lives.

WHEN WILL YOU HEAR FROM US NEXT?

These newsletters will be landing in your inbox ever first month of a yearly quarter. We will be bringing more guests, information and project updates as they do.

If you have anything you would like to be included in one, then please get in touch so we can consider it to be published.

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