



Friends of the Leeds Centre for Leukaemia, Lymphoma & Myeloma

Newsletter – March 2020

Reg. Charity No. 509071



Chairman- David Fox joined the Trustees in 2012 following his retirement from the NHS in 2011, after 37 years service. Most of his career was spent in Leeds and from 1999 until 2011 he was the senior manager for Haematology, Oncology and Palliative Care services in the Leeds hospitals. He played a key part in securing and managing the new facilities at St James's. He now undertakes a variety of voluntary work in the countryside.



Treasurer - Matthew Baker is a Solicitor and a Partner at Pinsent Masons LLP specialising in Commercial Property Dispute Resolution. He has been involved with the Friends for over 10 years since his father John Baker was treated on the ward in 1998. Matthew's Mother (Angela Knowles aka Miss February) and his Mother-in-Law (Lynda Logan aka Miss July) are two of the original *Calendar Girls*.



Carol has been Hon. Sec. since 2005. She has worked with haematology patients since 1977 when she was Outpatients Sister at the LGI. She was appointed Chemotherapy sister in 1988 and then Clinical Nurse Specialist IV therapy, Haematology from 1990 to 1997 when she retired. She returned as a part time research nurse until May 2011.



Derek Norfolk, was a Consultant Clinical Haematologist at the LGI from 1986 to 2006. From 2006 until retiring from clinical practice in 2011 he was Consultant in Haematology and Transfusion Medicine at Leeds Teaching Hospitals (LTH) NHS Trust and NHS Blood and Transplant. He continues to work as Associate Research and Development Director for LTH. Dr. Norfolk has been a Trustee of the FLCLLM since 1986.



Rod Johnson has been a consultant in Leeds since 2002. His main clinical and research interests are in the treatment of Lymphomas. He is currently the Lead Clinician for Haematology in Leeds and was appointed as a new Trustee in October 2017.



Graeme Smith was appointed Consultant Haematologist at the LGI in 1993 and was responsible for producing Regional Guidelines for the management of CML in Yorkshire. He was latterly Clinical Director of Oncology and has been a Trustee since 1993.



Consultant Haematologist, Roger Owen has particular interest in the diagnosis, treatment and disease monitoring in patients with Myeloma, MGUS, Waldenstrom's macroglobulinaemia and marginal zone lymphoma. Roger has been a Trustee since 2007.



Jean has lived and worked as a Careers Advisor in Leeds all her adult life. Now retired she continues a committed blood donor, volunteering with the Anthony Nolan 'R&Be' campaign giving talks in schools to encourage young people to register as bone marrow, blood and organ donors. Her husband Roger was treated for Leukaemia over many years at the LGI and they were grateful for the support given by the Friends to patients and their carers. She is delighted to be appointed as a Trustee to help to continue their valuable work.

Welcome to our latest newsletter and as always a big thank you to all our supporters, donors and fundraisers without whom we could not continue making a difference to patients, the service and research. Congratulations to our runners in the GNR, Hayley Pearson, Sara Elliot, Carla Smith, Bernardo Roa Jurado, Dr. Jennifer Clay and Dr. Christopher Parish. The total money raised by them and Michael Jeffery who sadly was unable to run due to injury was £4,257; a great result and very much appreciated. Thank you also to Lucy Holland- Selby for raising £586.25 at a Summer event. Once again the hard working **Blood Sweat and Cheers team** organised a Ball. It was a very enjoyable, fun evening and raised £5594.26. The total raised by the team and their supporters has now reached a fantastic £24,618.26; an amazing achievement and we can't thank them enough for their loyal support.

We can all look forward to another ball in the autumn. Rachel Jackson and daughter Megan have organised a **Roaring 20's Charity Ball** to be held at King's Croft Hotel, Pontefract on the 2nd October 2020.

You can read about 'The Friends' progress from our Chairman's update and changes in the Haematology department from Dr Rod Johnson's update. Sadly, our newsletter coincides with our lives being turned upside down due to the Covid-19 virus. I wish you all well and a safe journey though this difficult time.

Carol Bilbrough (Secretary)

Chairman's update March 2020

The Friends continue to be very successful through the considerable generosity of many people who all give their time voluntarily in fundraising. Our Just giving page www.justgiving.com/fllu/donate is a very simple but effective means of supporting The Friends. Some of you have run races such as the Great North Run whilst the Blood Sweat and cheers team have again held a very successful Ball. The Trustees have committed all of the funds raised to ideas from staff.

Over the past year the Trustees have been able to fund over £30,000 of requests from staff. The Trustees encourage staff to think of how we can assist them to provide the best possible treatment and care. Sometimes this is by funding individual patient recliner chairs or more comfortable treatment trolleys or assisting with aftercare by funding exercise bikes or by creating private space for relatives. Other requests enable staff to undertake their tasks more effectively such as 'l' pads for the doctors or by funding nurses attendance at conferences to learn of the latest ideas for caring for patients.

It is also a year since we started collaborating with the Chevin Socialites led by Lesley Noble and the TV fund is now administered by the Friends to enable Lesley and her team to focus on fundraising

and the 'Hug on a tray service'. The team raised enough money to fund free TV to all of the patients in 2019 and have now covered the costs for 2020; and they are already fundraising for 2021! As it costs about £26,000 per year—this is a remarkable achievement.

Our website www.friendsofleadshaem.org.uk has now been up and running for a year and with our Facebook and Twitter accounts helps us to share what we do and to secure more support for the Friends.

Thank you for your interest in the Friends.

David Fox (Chairman)

Medical update March 2020

There were quite a number of speculations, plans and possibilities mentioned in the update last year and I am pleased to say that most of them have been successfully implemented – or at least are shortly to become a reality. That represents quite a set of achievements and a lot of hard work and determination from many people across the department and the improvements and changes are always supported by the Friends for which we are all very grateful. Perhaps the two most important projects that have come to pass are the selection of our unit as a CAR–T centre (one of 10 in the UK) by NHS England and the opening of the new research centre, adjacent to our ward areas – the LCRF unit.

CAR – T is a new therapy that is expected to be a real change in cancer care for many diseases – in particular blood disorders. It uses genetically modified cells from patients to fight their own cancers and the process is complex, and currently very expensive – so to be chosen as one of the UK's 10 delivery centres is a real feather in our cap here the service is now fully funded and plans to open in the next 2 months – with a launch event here on the 1st of May.

The new research unit – LCRF – has just opened this month on level 3 in Bexley wing, just next to our wards, and is a very impressive, state of the art development in which we will be able to run our trials much more effectively.

Our staffing has seen some exciting developments with the addition of 2 advanced clinical practitioners (ACP's) and 3 Physician Associates – representing a move towards a more modern and varied clinical staffing model – we are very much at the forefront of these staffing developments and the people who have come into these posts have made a striking impression from the start.

Our Bone Marrow Transplant service has seen its busiest year on record so far, with over 60 patients receiving donor transplants here as well as 75 more having autografts (their own cells returned).

Consultant changes have included the appointment of Dr Mary Owen, a previous registrar and the departure of Dr. Anita Hill, who has left the PNH service for a new career in the pharmaceutical industry, The PNH service is being reconfigured with additional staff support following this and our above mentioned CAR-T service is also attracting new consultant staff so-as happens every year-we seem to keep growing as a department! In fact our biggest worry is where to put everyone sometimes!

On the nursing side we continue to maintain high standards and the feedback to the wards from our patients, which is regularly collected and shared, is extremely good and something we are particularly proud of. Claire Ferris, who has been with us for some years as a sister has been elevated to the position of our matron recently and also joins the trustees of the Friends – so through her we will have excellent representation in every sphere from the nursing body – and we congratulate her heartily.

So 2019 / 2020 has been another complicated, busy but rewarding year for the department and major developments have been pushed forward and completed. Thanks to the Friends for all their support and help with these many projects and we shall see what the coming year brings.

Dr. Rod Johnson (Trustee)

Upcoming event



Friends of the Haematology Wards
Leeds Cancer Centre
present a

Roaring 20's Charity Ball

Friday 2nd October 2020
King's Croft Hotel, Pontefract
7.00pm for 7.30pm

20's Attire (Optional)
Carriages at 12.30am

3 Course Meal
Live Entertainment, Disco and Prize Draw

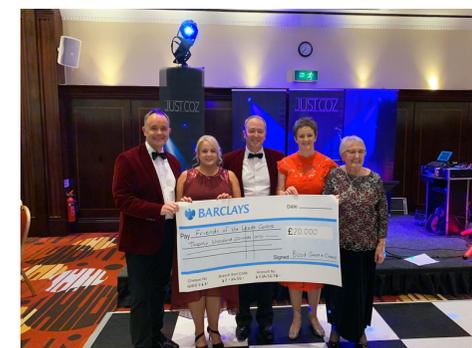
Tickets: £37.00 per person

For more details, please contact:
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Christopher Parrish / Jennifer Clay



Blood Red Ball



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