



# Friends of the Leeds Centre for Leukaemia, Lymphoma & Myeloma

Newsletter – February 2019

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 continue their valuable work'

I can't believe that it is now 11 years since Haematology services from St. James's, the LGI and Cookridge Hospital all moved into the new Bexley wing. 'The Friends' moved with them and have continued to raise funds to support patients, the service and research. The contributions we make would of course be impossible without the support of our committed fund raisers and the donations received. Thank you very much for your support and generosity which is very much appreciated.

You will find interesting updates overleaf from our Chairman David Fox and Trustee Dr Rod Johnson.

## Congratulations and a big thank you to the following fund raisers and their supporters:-

Teresa Butler raised £780 running in the Leeds half marathon.

Jane McGowan raised £775.44 trekking to Mount Everest base camp.

Jaqueline Gill, family, friends and N E Harness Racing raised a fantastic £10,000.

Rachel Jackson and daughter Megan organised a fantastic Ball and raised £2,500. Not to be left out, husband Mark ran in several 10 K events in Yorkshire and raised a further £1000.

It was a success story for all our runners taking part in the GNR .The Haem Team, Dr. Christopher Parrish, Kathryn Riley and Dr.Jiv Gosai raised £1,285.00, Emma Johnson and Shazia Sarela raised £1,500 and Dave Cropper of the **Blood, Sweat and Cheers team** raised £1,015. The team continue to give fantastic support to our charity and have now raised over £18,000.

Three families have kindly opened pages on the Just Giving site for donations in memory of a loved one. £2,267.00 was donated for Jason Dickinson, £880.00 for Caridwin Louise Thompson and £2,340 to date for Des Poole.

The recent Craig Ogden concert at The Grove Church Horsforth organised by Felicity Hickman and Martin Binks was a huge success and raised £1,635.31.for our charity.

**The Blood Sweat and Cheers team** are planning another Ball in the autumn so please keep checking on Facebook for the Date. The last one was a fantastic night out and a sell out event so you may need to get your tickets early.

Carol Bilbrough (Secretary)

 @LeedsCentreforLeukemiaLymphomaandMyeloma

 @Leeds\_Friends

**Enquiries about the FLCLLM to [carol.bilbrough@ntlworld.com](mailto:carol.bilbrough@ntlworld.com) Tel:01132943303**

## Chairman's Update February 2019

I begin with some sad news. Dr. Bryon Roberts who was the first Consultant Haematologist at the General Infirmary and who has been a Trustee of the Friends for 40 years died in January. He had led the introduction of many new treatments for patients and provided important advice to the Trustees on how the Friends could most effectively support the haematology service as it developed at the General Infirmary.

The past year has again been very successful with amazing generosity from individuals and groups. Our Justgiving site [www.justgiving.com/fliu/donate](http://www.justgiving.com/fliu/donate) has proved to be a very effective way of supporting the Friends. Once again we had runners in the Great North Run (GNR), Leeds Marathon and other events where supporters challenged themselves to help the haematology service. This year we have 10 sponsored places at the GNR.

One specific donation from a patient's family allowed us to purchase a bladder scanner for the wards and for a rehabilitation aid on each ward. The overall fundraising has enabled us to approve all the requests made to us by staff and patients over the past year. This includes a staff development day, electronic pipettes, new drug carts, fold away bed for relatives, rise and recline chairs and patient note easels. All of the items improve the care for patients and assist the nursing staff in their work.

Last year I mentioned that we now have Facebook and Twitter accounts and there is now a new website for the Friends, [www.friendsofleedshaem.org.uk](http://www.friendsofleedshaem.org.uk). This allows us to bring information about what we do, how to support us and who we are, into one place. It also enables us to list many key groups who may be useful to patients and their families and in addition we can publish the formal information that we supply to the charity commission.

I have previously mentioned our collaboration with the Chevin Socialites, the informal group who provide the 'Hug on a tray' service and who have fundraised to pay for the TV service at the patient bedside for the past few years. They have been so successful in their work that they have asked the Friends to take on responsibility for administering these funds and for the agreement with Hospedia who provide the TV service to the hospital. The Chevin Socialites will continue to fundraise for the TV service and to provide the Hug on a tray service. The Trustees have set up a separate account for funds specifically for patient TV, known as [Friends TV account](#), donations can be sent to Carol Billbrough, secretary of the Friends or to the Chevin Socialites.

**David Fox (Chairman)**

## Medical Update February 2019

It goes without saying that it has been another busy year across the department and the continued support from the Friends remains invaluable, both for financial help and as a focus for the teams to discuss and generate ideas for patient care. It's well known that staffing levels throughout the NHS are hard to maintain and our wards and day care areas are no exception, but we have managed to maintain an enviable level of quality in the wards which has been recognised repeatedly by the trust governance monitoring systems and this is down to the hard work and commitment of our nursing and admin team there who have done a fantastic job throughout this last year. The trust runs a regular feedback system for the wards asking patients and relatives to express their views in the care they experience and I am proud to say that the results of this for haematology are consistent and excellent.

Our research profile continues to develop and grow, with nationally recognised expertise in many sub speciality areas of haematology and a huge portfolio of trials available to the people of Leeds and also many referred from afar. New developments are being embraced including the exciting field of immunotherapy with genetically engineered T cells (CAR-T therapy)- we are already setting up trials in this and are hoping to be selected in 2019 as an additional centre to deliver this novel and cutting edge cancer therapy which is coming into use for some leukaemias and lymphomas already. Within Bexley wing there is a new research unit under construction which will be used by us and the oncology teams to accommodate more trial work and offer state of the art facilities to patients involved in many aspects of cancer research here. We hope to further benefit from this new build as it will release space for our other clinical areas too when ready – some of which is getting a bit cramped at the moment!

In the medical staff team we have seen (and are planning) changes this year. Our HMDS diagnostic lab consultants have been joined by Drs Hebah Ali and Alesia Khan although we were sad to lose Pedro Martin Cabrera who has moved on. We are developing 2 new posts in coagulation and red cell haematology respectively and we are trying to modernise our 'middle grade' registrar team with a broader clinical approach including advanced, nurse practitioners, physician associates and research fellows. This will hopefully make things more robust and improve delivery of clinic care and support for the others in our team.

So all in all it remains an exciting and developing place to work in and we hope the changes continue to make things better for all our staff and patients. The support of the Friends in this continuing endeavour is – as always been – warmly appreciated.

**Rod Johnson (Trustee)**



Dave Cropper, GNR



Mark Jackson, Yorkshire 10Ks



Jane McGowan, Mt. Everest

Base Camp



Teresa Butler, Leeds 10K



Emma and Shazia, GNR