

Here are some photos of items funded by the 'Friends' and details of a future event.



A Patient Observation Machine



A Patient Mobility Aid



Future Event

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

Newsletter – June 2021

Reg. Charity No. 509071

## Chairman's update June 2021

The past 15 months since my last message have been both very different but also business as normal for the Friends. All of our expected fundraising events were cancelled and with it the fundraising although many people were very kind and made donations. Our income has stood up very well and as before our Just giving link [www.justgiving.com/fllu/donate](http://www.justgiving.com/fllu/donate) has proved extremely simple to use and very successful. The ongoing help and support from the Blood Sweat and Cheers team is very much appreciated. The fundraising work led by Lesley Noble and the Chevin Socialites has continued with the team taking any opportunity that the government regulations permit to raise funds for the patients TV service. Indeed as with the previous year they had by last December raised all of the funds to pay for patient to have free bedside TV during 2021. They are currently working on funding for 2022 – a remarkable achievement.

Our strong financial position has enabled us to approve a wide range of bids from staff valued at £34884. Some of these are to keep the service up to date such as new observation machines. A patient mobility device, new patient room fridges and overbed tables. We have also been able to support staff by funding attendance at 'virtual' conferences to learn of the latest thinking about patient care and treatment. Staff also requested our support to fund the creation of a digital system for morphology and to adapt to manage in these different times such as a camera for a microscope so that medical staff are not crowded around the microscope for teaching and diagnosis, laptops for home working and remote patient consultations and an iPad for CAR-T patients to self monitor from home.

I am very pleased and proud that the Friends have been able to support the Department over this especially difficult year but as I frequently say, this is only due to the support you give to the Friends. There is a more detailed outline of the work of the Friends on our website [www.friendsofleedshaem.org.uk](http://www.friendsofleedshaem.org.uk) and it continues to be used by our supporters as well as those looking for information about the haematology service.

Thank you for your interest in our work.

### David Fox Chairman of the Trustees

Registration for entry into the **GNR on 12<sup>th</sup> September 2021** has been extended to midnight 26<sup>th</sup> July. Please contact me if you are looking for a place or for any enquiries about FLCLLM. [carol.bilbrough@ntlworld.com](mailto:carol.bilbrough@ntlworld.com) Telephone 0113 2943303

@LeedsCentreforLeukaemiaLymphomaandMyeloma  
 @Leeds\_Friends



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. Dr. Norfolk has been a Trustee of the FLCLLM since 1986



Claire is the Matron for Outpatient areas and Systemic Anti Cancer Therapies (SACT) within the Oncology Clinical Service Unit at St James'. She has held a variety of posts within Haematology including Junior Sister on the Haematology day Unit and then later the Senior Sister. Claire joined the Trustees in January 2020.



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. .

## Medical update June 2021

There is clearly no bigger issue to report on in the last year than the effect of COVID-19 on us all. It is strange to think that when I last wrote in March 2020 none of us really knew what was about to happen.

As you can imagine, the pandemic and all its many ramifications has affected everything we have done this year and continues to be a huge challenge. Despite it all, we have managed to continue treating all of our patients whose treatment cannot be delayed and through a huge effort of reorganisation and planning we have found ways of monitoring and keeping in touch with everyone when needed. This has been the most unexpected year for us all and I would like to thank all the staff throughout our department and trust who have helped to keep the show on the road, and also extend a huge thank you to all our patients for their understanding and patience through this time.

We have all now become used to new ways of working due to COVID, such as telephone and other electronic clinic 'visits' and a lot of remote blood testing and monitoring. Some of the changes – although they were forced on us – have actually proved quite effective and better for our patients, and when all this is over I am sure we will continue to work a bit differently to suit the changing times and the many different lifestyles that people have – there is never an experience you can't learn from. We have been grateful to the Friends for helping provide much needed technology upgrades allowing us to do this.

Despite it all, things have still developed however. After a delay due to COVID, we finally started treating patients for relapsed lymphomas with the new CAR –T therapy from March this year and that service is proving to be busier than expected - which is good! We have appointed a specialist consultant in CAR-T therapy – Dr Frances Seymour from Birmingham and also a dedicated nurse specialist – Kathryn Riley. The team has created a fantastic pathway for the treatment of these patients and we are very excited to be at the forefront of this cutting edge therapy.

It has been a year of staff development too – despite the COVID issues. We're proud to be a truly international unit. We have just appointed a group of international nurses to our wards as part of a development and education program in the trust and we have a mix of clinical staff now through links to university departments in Sri Lanka and Malta from where trainees are coming to work with us on the medical side. Add to that the Physician Associate and Advanced Clinical Practitioner roles we have embraced and the skill mix is broad and forward- looking.

As ever there are changes all the time in the speciality areas. In our PNH team, we have appointed Dr Petra Muus and extended our links with other centres through our coordinating role as the National Service base. Dr Peter Hillmen has retired and returned this year, remaining very involved part time and also through his University links. Our Haemostasis/Haemophillia team is now up to a good level of staffing with four consultants (it was one when I started here!) the most recent appointee is Dr Angela Kanny. We have also added to our Myeloid group with Dr Chun Huat Teh from Edinburgh.

I have one sad piece of news to give you – our great friend and colleague Dr Maria Gilleece had to leave us due to ill health in recent months and after a period of wonderful care in St Gemma's

Hospice in Leeds, she passed away in the company of her family in the third week of June. Maria started as a consultant Haematologist in Leeds around the same time as me (20 years ago now) and developed and led our Regional Bone Marrow Transplant Service and was a driving force behind its success. She had a national reputation in her field and is a great loss to us as a clinician, friend and source of help and advice. Our thoughts are with all those close to her.

Well I shall leave it at that – it has been a complex and often rather hard year due to COVID but I can honestly say that the department has never felt more cohesive, strong and determined. I am proud of what has been done through unexpected times to keep our patients safe and make sure their treatments can continue. At every level the staff have found new ways to manage and overcome these difficulties and we have been so grateful for the many kind words from our patients and their relatives and carers who have understood the changes we have had to make and shown great patience and fortitude.

So a big thank you to all our staff, to all those who attend our department for treatments and to the Friends and their supporters who do so much to help. We will all hope for a more settled picture throughout the country next year.

Best wishes

**Dr Rod Johnson (Trustee)**



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 Secretary 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



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.