

LAKPA 2019 Annual Report

I am delighted to present this annual report covering the period January to December 2019. It has been a busy year for us. Committee members have been active in focusing on our priorities as well as improving our day to day activities. I am most grateful to all Committee members for their commitment and support. The relationship we have built up with staff at the Trust has gone from strength to strength. I am particularly grateful to Dr Suresh Mathavakkannan, Dr Roger Greenwood and Maria Da Silva-Gane for their amazing support as Medical Liaison staff for LAKPA



LAKPA Committee

Overall we have made good progress on our six priorities for the year but remain very concerned about the lack of progress in relation to patient transport. Updates on each of the six priorities are set out below:

1.Better liaison with patients in Units, Home Therapies, Lister Ward 6B, Transplant and all other patients.

We have made good progress in improving our liaison, mainly through the work of our LAKPA liaison persons for the Lister (Andrew Bullen), Bedford (Tarsem Paul), Harlow (Peter Surridge), Luton (Tony Heath) and St Albans (Diana Large). Regular contact with the managers of the units is important in developing trust. Our financial support for social events and for Christmas decorations is now well established. Staff in units responded positively to celebrating World Kidney Day recently, for example:

Increasing public awareness of Deemed Consent and ensuring a positive message is received.

We have worked closely with David Brewer, Head of Engagement, and others in providing regular updates on the change in law to opt out in England. We included updates in each of our newsletters last year and supported the inclusion of the information in the Daily News which is sent to all Trust staff. We issued a press release which was covered by the local newspaper, The Comet, and have plans to continue this work over the next few months.

2. Supporting Shared Decision Making for patients, where the NHS objective is "no decisions about me without me".

We have worked closely with Dr Andrew Findlay who has been excellent in addressing this national concern highlighted by kidney patients. The Trust has established improved arrangements for engaging with patients at an early stage. We are confident that the support we have had on this priority from the Trust will result in improvements in the future.

3. Improving the provision of transport for patients to and from their dialysis centres.

We have made little progress on this despite efforts by LAKPA in raising this matter with the Clinical Commissioning Groups and the East of England Ambulance Service. We are most grateful to Andrew Bullen for highlighting examples of some of the poorest service

provided to patients. We have escalated these concerns within the lead CCG and have arranged an important meeting of all key stakeholders on 15 April 2020.

4. Funding some innovative projects to support patients.

We have been successful in funding a number of innovative projects. Our support for the Peer Support project continues and we are delighted that the staffing cost is now built into the Trust budget. We fund the Benefit Advisor Project and the project to improve monitoring of blood pressure for some kidney patients. We were invited by the National Kidney Federation to share our experience of establishing the Peer Support project at their annual patient's conference last year.

Our overall balance has been reduced from around £50k a couple of years ago to around £30k, in accordance with the decision we had made to do so. We recognise that our income in 2020 may decrease because of the uncertainty caused by coronavirus and will closely monitor our budget. We are most grateful to Anthony Byrne, our Treasurer, for his excellent management of our finances.

5. Relocation of the Luton dialysis unit

Progress on this has been delayed for a number of reasons. LAKPA is well represented by Tony Heath and Peter Surridge on the project group overseeing this development.

6. Day to day activities

Our newsletters are of a very high standard; thanks to the amazing work Ros Aird does as our Editor. Our website is impressive; thanks to Peter Surridge who ensures it is kept up to date. Our membership has increased substantially; from around 120 last year to over 425 now. This is as a result of efforts by the LAKPA Liaison persons and

the impressive management by Marcia Hamlin, our Membership Secretary.

Conclusion

I am most grateful to all members of the LAKPA committee for their commitment and support. I am grateful to Fiona Loud, our Vice-Chair, for providing a national perspective on some issues facing our members. Sadly, two of our committee members, Diana Large and Sandra Byrne are stepping down, we are most grateful to both of them for their support to LAKPA and kidney patients. Sandra has been a long standing member of our committee and has kindly agreed to help out when needed.

I am also most grateful to the support we have received from the Trust. We have worked closely with Dr Suresh Mathavakkanan, as the Clinical Director for Renal Services, for over seven years and are most grateful to him for his remarkable support to LAKPA. We welcome Dr Praveen Jeevaratnam as the new Director and look forward to working with him. We will determine our priorities for 2020 at our first committee meeting after the AGM, in April 2020. The obvious priorities are the implications of COVID-19 and patient transport.

Kirit Modi Chair, LAKPA.



World Kidney Day 2019



Alison and Mandy from Renal Support team



Bedford Unit's seaside outing



Organ Donation week 2019



Text 1: LAKPA at the NKF conference 2019



Seema's Annual Fundraiser



Harlow's 6th Birthday Party