

**MINUTES OF THE 35TH COUNCIL MEETING HELD AT THE STUDIO,
BIRMINGHAM, ON 23rd MARCH, 2013 at 2pm**

TRUSTEES PRESENT	Mr Kirit Modi	Chairman
	Mr Ray Mackey	Vice Chairman
	Mr M Abbott	Treasurer
	Mr R Price	Six Counties KPA
	Mr G Brown	Guy's & St Thomas KPA
	Mr J Higgins	Northamptonshire KPA
	Ms T Sinclair	Wessex KPA
	Mrs D Abbott	Gloucestershire KPA
	Mrs J Parker	Dudley KPA
	Mr D MacDonald	Wessex KPA
	Mr D Marshall	SAKA
	Mr W Beale	Bristol KPA
	Mrs A Beale	Bristol KPA

In attendance	Mr T Statham	Chief Executive
	Mr P Revell	Head of Fundraising
	Mr N Palmer	Head of Advocacy
	Ms M Parkin	Office Manager
	Mrs P Pinkos	Helpline Manager
	Mrs S Edwards	Accounts Administrator
	Mr E Maclean	National Advocacy Officer – Scotland
	Mrs K Cresswell	National Advocacy Officer – Wales and Northern Ireland
	Mrs L Callow	Regional Advocacy Officer -
	Mr M Davies	Regional Advocacy Officer – Midlands
	Mrs S Lines	Regional Advocacy Officer -
	Mrs L Pickering	Regional Advocacy Officer -

Plus 29 Official voting delegates (as per register) and 34 non-voting delegates as per the Attendance Register

A quorum of 30% of official representatives was met.

Kirit Modi welcomed everyone to the meeting.

601 APOLOGIES FOR ABSENCE

Had been received from: Sarah Orpen Dudley KPA, Judith Sideaway Dudley KPA, Sonia Moorhouse Guy's and St Thomas KPA, Michael Walker Lincolnshire KPA, Vivienne Dodds Walsgrave KPA, Dr Margaret Ince Leicestershire KPA, Dennis Crane MBE, North East Advocacy Officer and William Johnston NIKPA, and Richard Van Roon SCKPA.

601 MINUTES OF COUNCIL MEETING HELD ON SUNDAY 14th OCTOBER, 2012.

Minutes of the Council meeting held on 14th October, 2012. It was proposed by Denise Abbott, Gloucestershire KPA, seconded by Clement Maynard Birmingham Heartlands KPA and agreed unanimously to accept the minutes of the meeting held 14th October, 2012.

602 MATTERS ARISING

In response to a comment from Simon Lloyd of Tyneside KPA relating to making the AGM a full day for KPA's, Kirit Modi responded stating this meeting had been in part as a result of the proposition received Mr Lloyd continued by stating a regional support day had been organised in his area for 14th September. Part of that meeting would focus on the achievements of the NKF. Linda Pickering NKF Advocacy Officer is assisting with

the organisation of the event. Kirit Modi stated he was delighted at the venture which he stated was very welcome news and hoped other parts of the country may follow suit.

603 NKF ROADSHOW 2012 – Hinckley Island Hotel 11th – 13th October, 2013

Barbara Morris gave a short report on the proposals for NKF conference 2013. The theme of "Together we Can" had been decided upon. The programme was designed to work with KPA's throughout the day. She asked KPA's to support young patients to attend. The programme also included a section for carers, and a debate on the pros and cons of home dialysis. The Friday evening reception had been cancelled in favour of allowing the Friday evening meeting to run slightly later 7.30 to 8.30 to allow as many delegates as possible to attend. Four Sunday morning workshops were planned and Ms Morris asked everyone to support them. NKF Executive members Tracey Sinclair and Mick Walker are the main contacts for young patients and they will be looking at ways in which to encourage them to attend. A motivational speaker is being sought. Entertainment will follow the Gala Dinner.

604 Open Forum

John Fulton Scottish Kidney Federation (SKF) asked what the NKF is doing to ensure death certificates are recorded correctly. A number of people are dying from kidney disease which is being recorded as a secondary factor.

Barbara Morris stated death certificates will carry the main cause of death first, if that is not kidney disease then that will be recorded as secondary.

Bill Macdonald –SKF stated they would be holding a one day conference on 18th May in Perth. The venue was one minute from station, and a theme of Circle of Life had been agreed. Guest speakers had been organised. Ewen Maclean NKF National Advocacy Officer for Scotland was working closely with SKF on the event.

Simon Lloyd Tyneside KPA raised the question of transport becoming a standardised issue:

1. Patient should have clearly defined collection time
2. 30 minute standing time
3. Journey no more than 30 minutes
4. Arrive at dialysis 30 minutes
5. Collected within 30 minutes afterwards
6. Should be more than 30 minutes before getting home.

He stated if this regime could be applied it would make a tremendous difference to the lives of hospital dialysis patients.

David Myers Royal Free KPA responded to a question raised by Steve Caddick North West Region KPA in relation to concerns over a patient on dialysis, by stating, the first point of contact should be the person who runs the unit. If there is no response, go to management level until answers are received. The approach should be why is this happening? And what can be done to improve it? Issues should be put in writing as this puts it on record. Follow up one week later. He continued by stating Royal Free Hospital renal personnel are very committed and always ready to help.

In response to a question raised by Nick Flint Queen Elizabeth Hospital KPA in relation to NKF increasing their own fundraising activities which could encroach on local KPAs, Ray Mackey stated he was disappointed in the response as NKF was also a charity which needed funds to function. He explained NKF sponsorship from industry had fallen dramatically over the last few years and NKF needed to branch out. The fundraising being done by NKF was not to take away from local KPA's but add to their funds by becoming involved with joint fundraising events. The annual draw held by NKF gave a 60% return to KPA's. David Myers Royal Free KPA stated the most successful event during the year is the KPA annual members draw. The 60% income which individual KPA's receive is excellent. KPA's should look more to working together with NKF on similar schemes which the KPA's could share in as well. He felt that could work for all parties. Jason Kidd West London KPA suggested NKF should take a more national stance so KPA's can look after the regional areas. Bill MacDonald SKF stated he had no issue with the annual draw as it was held at a different time of year. He felt NKF keeping a high profile nationally could only be good for all KPA's. Timothy Statham stated he felt that it would be a shame if

some KPA's did not want to share fundraising activity with the NKF. He felt the opportunity should be seized to unite kidney patients and result in national support for the kidney patient cause. Clement Maynard, Birmingham Heartlands KPA, stated it was of little use asking the same people to support the charity when those people are already struggling. He suggested the fundraiser needed to find new outlets to make up the shortfall. Ray Mackey stated all views and opinions had been recorded and would be discussed by the Executive Committee in April.

Kirit Modi NKF Chairman suggested it was time to work together and asked all KPA's to provide information on what they were doing for National Transplant week which was now organised by National Health Service Blood and Transplant (NHSBT) and would take place 8 – 14 July. NHSBT had requested donations for the "through the lens" films which would promote organ donation.

He requested that everyone complete the evaluation sheet provided with the information pack.

Andrew Bullen Lister KPA stated he felt the information covered had been excellent. He continued by stating Lister KPA had two satellites both with free car parking. They had excellent relationships with the Asian community. Sashi Patel had raised funds locally by placing collection boxes in Post Offices and major shops. Over 10 years he had raised £80K which had been used for dialysis machines. Sashi had now returned to India and Smokey had taken over his role. He had organised a fundraising curry party which 200 people had attended. He made all the food, arranged an auction etc and the event had raised £2,300. He said it was great to be part of the committee and a great example of how to work together.

Ewen Maclean Advocacy Officer Scotland shared a success story of setting up the Inverclyde KPA. However, this had suffered a major setback from a blockage created by hospital staff, who would not allow anything to be arranged in the name of the KPA unless it was cleared by the sister. This was preventing the group growing as they could not secure names and addresses of patients. He asked for suggestions on how this could be overcome. Kidney Life is being delivered to the unit. Marion Higgins Northamptonshire KPA stated they gave the ward clerk their list which she then checks against her list. The KPA then provides application forms and the ward clerk provides address labels. Some patients respond and join as members. Ewen Maclean stated the sister did not believe patients should be involved in any way. NKF to get involved with the situation.

There being no further business, the meeting was closed in order for the KPA Day to continue.

ChairmanDate