**Kidney Care UK Advisory Group**

**Post** Member of Kidney Care UK Advisory group – lay membership

**Background** The Kidney Care UK is the largest UK charitysupporting people and their families affected by kidney disease through advice, grant aid and research. Our objective is to improve quality of life for people with kidney disease. The charity wishes to engage a range of advisors who have experience of kidney disease, whether as individuals or through family members. A national group is to be established to advise the charity on its activities and bring a wider representative set of views than we have through our trustees and employees. The group will bring the unique perspectives of service users and carers to help us improve what we do now, and the future spread and dissemination of our work and projects.

**Objectives**

* To gain feedback on national patient issues currently impacting on Kidney Care UK e.g. patient choice, peer support, self care, holidays etc
* To guide and influence the effectiveness of Kidney Care UK activities such as patient grants, new patient leaflets, magazine content, website content etc
* To advise on opportunities and areas in which Kidney Care UK could offer more effective support for patients
* To advise on opportunities for fundraising
* To represent a wide range of experience for the patients we serve
* To increase awareness and dissemination of our work and the grants we make
* To provide a representative response to the media

**Membership** The group will consist of up to 18 members including a chairperson plus one trustee and the Policy Director. Members and the chairperson will be selected following an open recruitment process through all available means, such as kidney charity websites and social media. Membership will include the following experience areas, appreciating that a member or someone in their network may have experience in more than one of these:

CKD stages 1-4

Renal Replacement therapies (peritoneal dialysis, in centre or satellite haemodialysis, home haemodialysis, transplantation).

Membership is open to family members or carers as well as people with kidney disease.

**Principal responsibilities**

**1. To attend group meetings**

Advisory group meetings will usually be at four times each year. They are an opportunity to meet fellow group members, to review recent developments and discuss current and forthcoming activities. There will be paperwork to review before and after the meetings, and members may be asked to speak about particular subjects in which they have experience.

**2. To contribute during group meetings**

You will be asked to contribute to the discussion to ensure that user and carer priorities and experiences are reflected, and that decisions take into account issues of concern to all. Members are asked to show respect to everyone attending the meeting. The group will not discuss personal issues concerning the care of an individual.

**3. To take part in group communications**

You will be expected to take an active part in regular group communications such as emails. There will also be occasional telephone calls and telephone conference calls (no personal charges). We understand that members may well be patients, and sometimes health problems or other issues can temporarily delay or prevent responses to communications. However if members do not attend meetings and calls 3 times in a row without good reason their membership may be terminated.

**5. To alert the charity to new initiatives and opportunities**

To make Kidney Care UK aware of local initiatives, grant-giving or fundraising opportunities and share these with the charity on an ad hoc basis.

**6. Media or case study representation on behalf of the charity (optional)**

To speak about your experience (or that of someone in your family) to the media or an audience on behalf of the charity, with support from and when requested by the charity.

**7. Attendance at other meetings or conferences (optional)**

To represent the charity at meetings or conferences. Reasonable travel expenses will be paid in this case.

**8. Consultations**

To provide advice on consultations in areas where Kidney Care UK is a stakeholder.

**9. Research**

To provide commentary on potential research projects either by email or during PAG meetings.

**10. Confidentiality**

All group members will be asked to maintain the confidentiality of Kidney Care UK discussions and grant applications unless otherwise stated.

**General** Members of the Patient Advisory Group agree to be bound by the Terms of Reference as defined in this document by their acceptance of a position on the Group.

**Duration** The term of office is three years, with the option for a one year sabbatical which will not count towards the three years. Group members can be re-elected one year at a time for up to a further three years.

**Benefits to members**

* **Personal development**: through involvement in our work, members will be offered opportunities to develop knowledge and skills in areas related to advocacy.
* **Personal satisfaction** in making a much-valued contribution to a charity supporting kidney patients in the UK.

**Remuneration** Travel and associated expenses incurred by members in their activities as a member of Kidney Care UK advisory group will be reimbursed according to Kidney Care UK expenses policy on presentation of receipts and completion of an expense form. Membership of the group is voluntary. For attendance at the meetings members can receive an honorarium, or a grant for a similar amount can be made to the member’s unit/hospital if preferred.

**Communication** The group will meet four times each year. The group will communicate regularly by email and occasional telephone conferences. Minutes of the meetings will be made available to Kidney Care UK Trustees.

**Administration**

Kidney Care UK will support the group with handling meeting arrangements, expenses and general communication.

**Status**

The Kidney Care UK Advisory Group will be a forum providing information and guidance that it is hoped will enable the charity to operate more effectively. However Kidney Care UK Directors will retain ultimate responsibility for and have an unfettered discretion in relation to the management, policies and governance of the charity and accordingly, do not bind themselves to accept recommendations made by the Advisory Group.

**Application process** Please complete the application form and email it to [fiona.loud@kidneycareuk.org](mailto:fiona.loud@kidneycareuk.org) or by post to: Fiona Loud, 3, the Windmills, St Mary’s Close, Turk Street, Alton, Hants GU34 1EF