

### **Main Aim**

The PKD Charity Research Advisory Board (RAB) is a standing committee of the Polycystic Kidney Disease (PKD) Charity.

The RAB, from 27 September 2013 will replace the PKDC Scientific, Clinical and Research Advisory Board (SCARAB) (in existence since April 2006) retaining the overall aim to further innovative basic, translational and clinical research to develop understanding of polycystic kidney disease processes, facilitate new therapies and improve patient management related to all forms of PKD.

The RAB will advise on the support of nationally-competitive investigator-led projects. The intent is to direct PKD-specific research funds to fund projects that would not (yet) be eligible for support by national funding. Normally, these would be early-stage projects requiring “pump-priming” for 12-18 months to derive sufficient evidence to be competitive for longer-term, larger scale national entity funding.

### **General Terms of Reference**

- a) To advise the Trustees of the PKD Charity on the special needs of research and allied projects.
- b) To receive and consider requests for research support and related facilities.
- c) To make recommendations regarding expenditure for research purposes by the Trustees of the PKD Charity, to recommend grant awards accordingly and to monitor their progress and outcomes.
- d) To consider any aspects of research and allocation as may be requested by the Trustees of the PKD Charity.
- e) To provide advice and support to the Trustees on reporting and dissemination of research results.
- f) To review relevant publications from the PKD Charity.
- g) To assist the Trustees with the production of nationally accredited information on health and social care aspects of PKD.

### Objectives

- a) To maintain an active research portfolio and to assist with achieving an academically stimulating climate which will assist in attracting basic, translational and clinical researchers of high calibre.
- b) To provide the means by which young scientists and clinicians in training have the opportunity to become involved in PKD research projects.
- c) To recommend and/or endorse, annually, members of the PKD Charity's Advisory Panel for the writing and/or review of relevant medical or scientific information.

### Limitations of RAB Funding

- a) Awards will only be made available to those holding appointments in nationally accredited universities, medical schools or NHS hospital trusts or to registered students or fellows at a nationally accredited university, medical school or NHS hospital trust.
- b) Awards will only be made to projects that will take place principally within nationally accredited universities, medical schools or NHS hospital trusts.
- c) Detailed guidelines for applicants for research grants etc are provided in separate papers (Appendix A) and will be published on the PKD Charity website on approval by the Trustees.

### Composition of the RAB

The total voting membership will be:

- The Chair
- A representative of the PKD Charity
- A lay member (to be advised by the PKD Charity)
- 2 ordinary members representing the basic/translational sciences
- 2 ordinary members representing clinical/translational sciences
- Non-voting administrator to the RAB

The Chair and Vice-Chair of the RAB will be elected from the ordinary members of the RAB.

The PKD Charity Trustees will ratify the appointment of the Chair and Vice-Chair.

The Chair of the RAB and the PKD Charity Trustees will request nominations for vacancies on the RAB. The Chair might when seeking members advise which disciplines and expertise would complement the RAB.

The Term of Office of the ordinary members of the RAB will be three years renewable for a single further three-year period. It is expected that there will be staggered retirement from the RAB, to permit continuity of experience. The Chair and Vice-Chair will have their terms of office reviewed by the PKD Charity at not less than 4 yearly intervals and renewed at the discretion of the Trustees of the PKD Charity.

Notice of removal from the RAB may be given in writing by the PKD Charity, or Chairman. This will be given in writing and noted in the minutes of the RAB.

The quorum for a meeting of the RAB will be not less than 4 voting members.

The RAB may on occasions advise the PKD Charity of any requirements.

The RAB may, from time to time, co-opt ad hoc members as required for specific tasks.

## Organisation and Role

The RAB includes in its role:

- a) Provision of project grants of up to two years in duration in line with the research strategy and funding objectives of the PKD Charity.
- b) Support of Clinical Training Fellowships (opportunities for young clinicians).
- c) Support of Non-Clinical Training Fellowships (opportunities for young scientists).
- d) Support of PhD and intercalated Studentships.
- e) Support of Health Services Research fellowships.

The RAB will meet regularly during the year.

Meetings will be concerned with:

- a) The undertaking of a rigorous decision making process including peer-review analysis, prioritization and recommendation of grant applications.
- b) Consideration of specific requests in terms of student and fellowship co-funding.
- c) Monitoring of the RAB 's financial affairs.
- d) Understanding of strategies, policies and priorities of the PKD Charity and reviewing progress of recent and existing programmes.

### Conflicts of Interest

For the RAB to function effectively, it must maintain its status and credibility as an independent committee of the PKD Charity. Members must not only avoid activities that create a conflict of interest, but those activities that may represent a significant appearance of conflict of interest that may impair the credibility or status of that Committee.

Conflict of interest means any financial or other interest which conflicts with the services of any RAB member because it either impairs the member's objectivity or it could create an unfair advantage for any person or organisation.

Any RAB member shall be eligible to apply for PKD Charity research funding during his/her tenure. When the review of his/her application is presented to the RAB, the applicant must withdraw from the discussion. In the case of the Chair being an applicant, the Vice-chair shall assume the chair of the RAB for that discussion.

In addition to the observance of professional standards, the members of the RAB agree to abide by the PKD Charity's Ethical Policy (Appendix B and also published on the PKD Charity website).

### Administrative and Financial Support

This will be clearly identified in terms of activation and cost. The staff concerned will be directly accountable to the CEO of the PKD Charity.

Travel expenses incurred within the UK (standard/economy class) will be paid for those members attending the RAB meetings.

### Reporting

Minutes of all meetings of the RAB will normally be taken by the administrative assistant, reviewed by the Chair of the RAB and sent to the CEO of the PKD Charity as soon as available for submission to the Trustees.

It is expected that the opportunity be taken at one meeting each year to review with representatives of the PKD Charity the past and future programme as well as any special areas of research that the PKD Charity would wish to be considered for special emphasis.

The chairman of the RAB or nominated person will be a co-opted, non voting member of the PKD Charity Trustees meetings.

Adopted: 27 September 2013

Signed: Margaret Pope

Position: Trustee

On behalf of the PKD Charity Trustees