

KIDNEY RESEARCH TO BENEFIT PATIENTS

Professor Charles Pusey, Chairman of Trustees, The National Kidney Research Fund

As Chairman of Trustees for The National Kidney Research Fund, I am delighted to present a view for the future of the Fund that will build on more than 40 years of charitable support for research into kidney disease, and continue to influence kidney research for the benefit of the patient well into the future. This year is of particular importance for people with kidney disease, with the publication of the National Service Framework (Part One) and the Human Tissue Bill.

Since its formation by the Renal Association in the 1960s, the Fund has been dedicated to the prevention and treatment of kidney disease. Our mission over the life of the Fund has been consistent and we see no immediate reason why it should change. However, we do see our core activities developing in the short to medium term, as we endeavour to increase the efficiency of our fundraising operations and allow more funds to be made available for charitable activities.

The main aim of the Fund continues to be the funding of high quality research into renal disease. Like other funding bodies, we are trying to focus this research, where possible, on projects which will lead to clinical advances in the near future. Although at present no separate funding is ring fenced for clinical research, the Trustees are actively considering how the research budget might be better subdivided. Our programme of research funding currently includes project grants, training fellowships, senior fellowships and PhD studentships. We plan to continue all of these initiatives, although there are discussions about modifying senior clinical fellowships to come in line with the National Clinician Scientist Fellowship Scheme. We are currently supporting 43 projects, 12 training fellowships, 6 senior fellowships, and 10 PhD studentships, which cover every aspect of renal disease. With a current commitment of over £9 million, the Fund is the largest supporter of renal-specific research in the UK.

Our main objective over the next three years will be to increase our funding of research by more than 50% whilst continuing to invest in the areas of public awareness, education for patients (particularly in high-risk groups) and direct patient support. To achieve these difficult goals we have to develop the income streams of the organisation and look for a better and more sustainable 'balanced portfolio'. This could result from additional efforts in donor development, and an expansion of our relationship with Corporate and Trust donors in both restricted and non-restricted funding arrangements.

The Fund has made considerable efforts to develop governance systems that give confidence to our stakeholders that funds are being given to projects of the greatest scientific merit which will bring benefit to kidney patients. Of particular note is the Scientific and Clinical Research Development Committee, chaired by Dr John Bradley, which ensures that research activities fulfil the specific objectives set by the Council of Trustees. The membership of this committee includes the Chairman of the Research Grants Committee (Professor Peter Mathieson), Trustees and staff of the Fund.

We are working in partnership with other organisations to develop a variety of "special projects" within our *Pathfinder* and *Horizon* initiatives. These are focussed on areas which the Fund regards as of strategic importance, and are either funded jointly with Research Councils, other charities, trusts, individual donors or the pharmaceutical industry, or are facilitated by the Fund with no direct funding commitment. Our *Pathfinder* initiatives involve DNA/data collection in glomerulonephritis, vesicoureteric reflux, and polycystic kidney disease (pending), and our *Horizon* initiatives include the fields of vascular calcification, renal artery stenosis, co-morbidity and long-term survival post transplantation, and membranous glomerulonephritis. These projects are clear examples of the extent of our commitment to improving patient care through collaborative ventures. Details of our ABLE programme targeted at 'at-risk' communities, will be covered in a separate presentation. In terms of public awareness, the Fund continues to raise its profile in the political arena throughout the UK, and last month produced a second report on renal disease for the Scottish Executive. The National Patient Advisory Group provides advice on the best way in which we can help patients, and these include the National Kidney Helpline, joint appeals with hospitals, and patient support grants.