Renal Association 2001 - 2010

John Feehally & Christopher G Winearls

Introduction

As Stewart Cameron reminded us in his engaging history "The First Half-Century of the Renal Association, 1950-2000"[1] , the Renal Association is the oldest continuously active nephrology society in the world. Founded on 30th March 1950 at the CIBA Foundation in London, it comfortably predates the next national nephrology society to be established, Società Italiana di Nefrologia [1957], and the International Society of Nephrology [1960]. Both the Société de Pathologie Rénale and the Nordic Society of Nephrology actually held their first meetings in 1949, but unlike the Renal Association have not met continuously since then. The American Society of Nephrology, now the largest national nephrology society, was founded in 1966.

Stewart Cameron traced the Renal Association's history from its foundation as a small scientific society in 1950 to its role in 2000 as a large, multifaceted professional society. This supplementary history now traces the story of the Renal Association in the subsequent ten years to its 60th Anniversary in 2010. The goals of the Renal Association as the society of professionals committed to the kidney (be they clinical nephrologists, pathologists or scientists), in the United Kingdom have not changed. It has grown in size and complexity over the last decade in response to the expansion and change in the scope of nephrology as a specialty; responding to changes in the clinical, scientific and political environment. This evolution, some may say revolution, was driven by the Association's leadership to ensure that it fully represents its entire membership.

We recognise the risks of interpreting events when too few years have passed to give a balanced perspective. On the other hand since the two authors of this chapter were officers of the Association for the major part of this decade, we hope that we are well placed to describe what actually happened. More important than our own memories of events, has been the near complete electronic record of the Association's business through the decade, including minutes of the meetings of the Trustees, Executive Committee, Boards, and various committees. We have also prompted our colleagues among the Association's leadership to confirm our own version of events.

Cameron's history was also enlivened by cameos of the idiosyncrasies of the great figures of the past; this we have resisted here, reckoning it better not to muse about our contemporaries and colleagues. But perhaps this brief history is duller for that omission.

Officers of the Renal Association [Table 1]

Presidents

Gwyn Williams, Renal Association President at the time of the successful 50th Anniversary celebrations in 2000, was succeeded by Andrew Rees (b. 1946) in Aberdeen, in 2001 [Figure 1].

Figure 1 : Andrew Rees – President 2001-2004

Rees, who was Regius Professor of Medicine in Aberdeen, used his presidency to initiate a modernising programme of the Association's organisation and structure. He recognised the need for stronger financial governance and oversaw the appointment of an Honorary Treasurer. In 2002 he set up a Clinical Affairs Working Party to clarify the role of the RA in determining and influencing clinical policies. He had already led a rationalising effort as chair of the Joint Committee on Renal Medicine between the Renal Association and the Royal College of Physicians of London, which improved the function of that committee [see below, RCP London, page 26]. He also strengthened the governance of the Renal Association's rapidly growing and extremely successful UK Renal Registry through the establishment of a Renal Registry Management Board and the appointment of a Registry Manager.

Rees' successor, John Feehally (b. 1951) [Figure 2], Professor of Renal Medicine in Leicester, President from 2004-2007, completed the new Renal Association structure,

[1] http://www.renal.org/whatwedo/Publications.aspx

overseeing the election of both Clinical and Academic Vice-Presidents, and followed Rees as Chair of the Registry Management Board (a role now linked to the position of Immediate Past President).

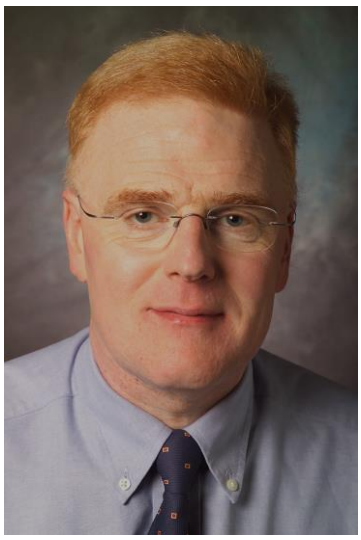


Figure 2: John Feehally - President 2004-2007

The rapid growth of the Renal Association's membership caused concern in some quarters about the ability of the Association to represent its ever wider constituency of nephrologists throughout the UK. Many were primarily clinical nephrologists and some thought their interests were increasingly remote from the original focus of the Renal Association on the science of the kidney. Some members had already established other organisations to reflect these different perspectives – notably the Society for District General Hospital Nephrologists and the British Renal Society [see below, page 27]. Feehally responded to this by making a series of visits to every UK renal unit during his Presidency. This was a major task and was greatly appreciated by members working in a challenging and sometimes dispiriting environment. The conclusions and recommendations were described in his report *'A View of UK Nephrology, based on observations from visits to all UK renal units, 2004 – 2007'* [2]

The election of Feehally's successor as President created an unusual set of circumstances. The well established process required identification of a President Elect twelve months before accession to the Presidency, and the membership elected Donal O'Donoghue, Consultant Nephrologist in Salford, as President Elect in 2006. However as the time for him to succeed Feehally approached, O'Donoghue was invited by the Department of Health to be the first National Clinical Director for Kidney Care for England. The two roles created inevitable conflicts of interest. So, with the full support of the Renal Association Executive Committee, O'Donoghue stood down as the Association's President Elect as soon as he accepted the position of National Clinical Director.

[2] http://www.renal.org/whatwedo/Publications.aspx

A further election at short notice was required. Peter Mathieson [b. 1959], [Figure 3], Professor of Renal Medicine in Bristol, was elected and had only three months instead of the usual twelve months as President Elect to familiarise himself with the role and its challenges.

Figure 3: Peter Mathieson – President 2007-2010

Mathieson climbed this remarkably steep learning curve with ease, undoubtedly assisted by the strong leadership structure, including the two Vice Presidents, then in place (see below). Mathieson's presidency saw continuing modernisation, communications and elections became entirely electronic and growth in size to more than 1000 members. He led challenging negotiations with the Royal College of Physicians about the new Specialty Certificate Examination in Renal Medicine [see Education & Training, page 23] which led on to a burgeoning coalition with other medical specialty societies. He also strengthened representation of the devolved nations of the UK on the Renal Association Executive Committee

The election of Charles Tomson (b. 1956) [Figure 4], Consultant Nephrologist from Bristol, as President Elect to succeed Mathieson in 2010,coincided with a decision of the Executive Committee that in future the tenure of the President [and therefore also the Immediate Past-President] would reduce from three years to two years.

Figure 4: Charles Tomson – President 2010-2012

This change recognised the increasing multifaceted demands made on both the President and the immediate Past-President, and the many excellent candidates for these roles within the growing Renal Association membership.

Honorary Secretaries

At the beginning of the decade Tim Goodship was succeeded as Honorary Secretary by Adrian Woolf [Professor of Paediatric Nephrology, Institute of Child Health, London], followed in turn by David Goldsmith [Consultant Nephrologist, Guy's Hospital, London] from 2004, and Lorraine Harper [Senior Lecturer in Nephrology, Birmingham] from 2008.

The role of Honorary Secretary changed as the Renal Association secretariat took increasing responsibility for a wide range of routine administrative tasks such as membership renewals, which were previously the role of the Secretary. Communications to the Association's members have also been transformed and are now almost exclusively electronic. But the role became no less demanding; not least because of the major responsibility of the Secretary in the Scientific Programme Committee for the Annual Conference. Increasingly complex planning has been required, from 2005 onwards, since the majority of annual conferences are now being organised jointly with other organisations [see Annual Conference, page 13].

Honorary Treasurer

Financial management was provided by the Renal Association secretariat, Triangle 3, from 1997 but there had not been a supervisory financial role among the RA volunteer

leadership following the retirement in 1996 of the RA's longstanding Treasurer Peter Mullen OBE (d. 2005) (formerly of the National Kidney Research Fund). Andy Rees during his presidency recognised this was no longer tenable, and obtained the agreement of the Executive Committee for the appointment of a Renal Association Honorary Treasurer, who also became a Renal Association trustee. The position was first held by John Feehally [2001-03], then by Donal O'Donoghue [2003-06], Stuart Rodger [Consultant Nephrologist from Glasgow] [2006-10], and Jonathan Fox [Consultant Nephrologist from Glasgow] [2010]. The broadening responsibilities of the Treasurer involved working closely with the RA secretariat to provide financial and accounting information to reassure the Trustees and Executive Committee of the financial stability and probity of the Association, including the Renal Registry. A particular issue, resolved during Stuart Rodger's tenure was clarification of the complex VAT situation especially in relation to the Registry.

Table 1: Officers of the Renal Association, 2001-2010

	President	Secretary	Treasurer	Clinical VP	Academic VP
2001	Andrew Rees	Adrian Woolf	John Feehally		
2002					
2003			Donal O'Donoghue		
2004	John Feehally	David Goldsmith		Christopher Winearls	
2005					
2006			Stuart Rodger		
2007	Peter Mathieson			Kevin Harris	Caroline Savage
2008		Lorraine Harper			
2009					
2010	Charles Tomson		Jonathan Fox	Martin Raftery	Bruce Hendry

Secretariat

In the mid-1990s the Renal Association realised that it was no longer possible for its affairs to be run by an honorary secretary from an NHS or University office with some modest administrative support. In 1997, the Association therefore established a successful relationship with Triangle 3 (a commercial arm of the British Society of Immunology), its first professional secretariat, and this ended in 2006 when Triangle 3 unexpectedly decided it no longer wished to provide association management services. After a thorough tendering and interview process, the Renal Association Trustees chose MCI Ltd, the UK branch of an international association management company, which since 2006 has provided the Association with secretariat and conference organising services from its offices in Petersfield, Hampshire. The cost of those services has become a major part of RA expenditure and has brought a growing professionalism to the work of the Association increasingly necessary as the complexity of RA structures has expanded and the number of committees, boards, and meetings has grown.

Structure and Organisation

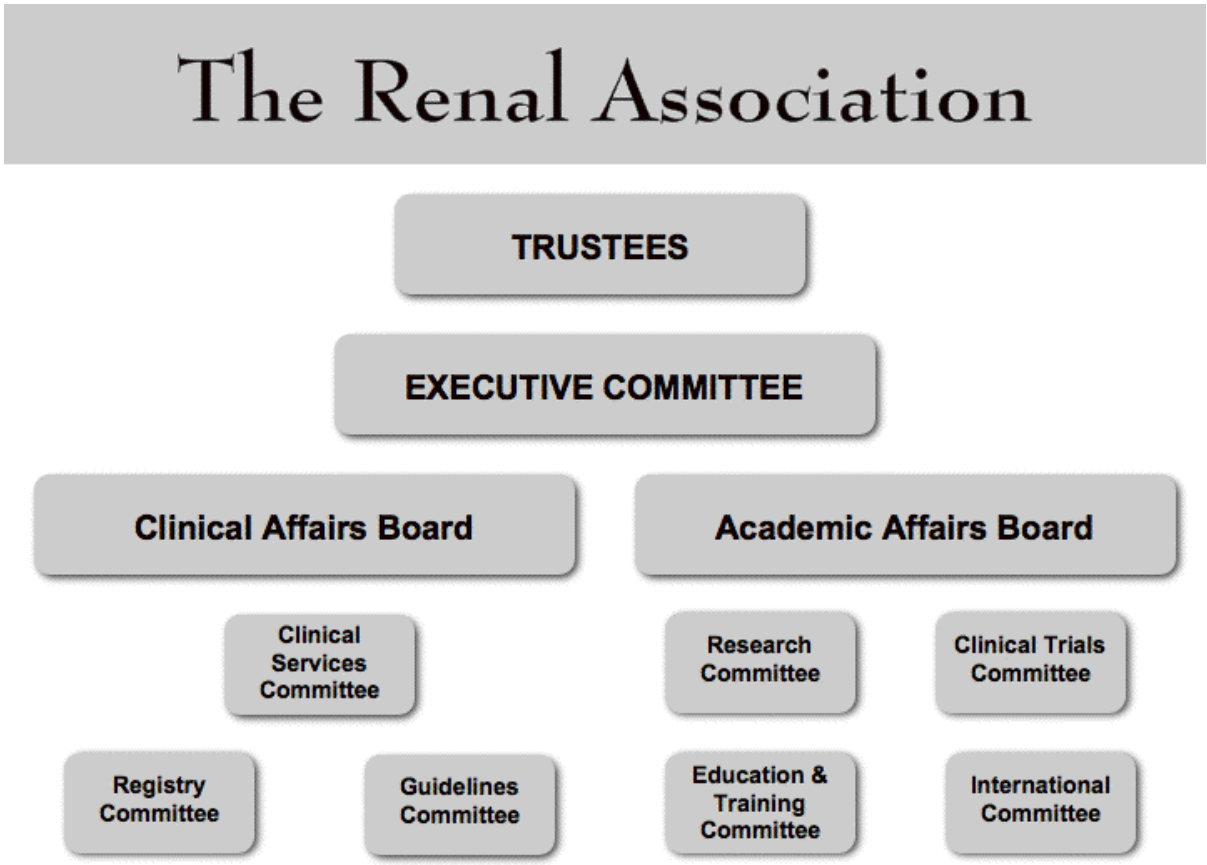
Until 2002 the Renal Association leadership structure had remained remarkably "lean". The President, supported by the Honorary Secretary, took on a broad range of onerous organisational and representative tasks. Financial management had been provided by Triangle 3 until the appointment of a Treasurer. Andy Rees recognised the increasing burden of expectation on the President to become involved in a wide range of initiatives led by the Department of Health in England [with initiatives with similar intent in the devolved

parts of the UK] which were likely to have a crucial impact on the development of clinical services for people with kidney disease. The decision had been made in 2001 that a National Service Framework for Renal Services in England would be prepared and this was followed by the establishment of a Renal Advisory Group at the Department of Health, first chaired by Robert Wilkinson [Newcastle], succeeded in 2004 by Donal O'Donoghue, who was later appointed as the first National Clinical Director for Kidney Care for England (the 'Renal Tsar'). The Renal Association needed a structure and leadership to be able to respond to these many issues and ensure that nephrologists had a leading voice in the rapidly changing planning and delivery of renal services in England and throughout the UK. Andy Rees established a Clinical Affairs Working Party in 2003 chaired by former Honorary Secretary, Christopher Winearls, which recommended that the Renal Association appoint a Clinical Vice President who would chair a Clinical Affairs Board, membership of that board to include Chairs of the committees whose work related to the clinical arena – the Clinical Services Committee, the Registry Committee, the Clinical Practice Guidelines Committee - as well as two elected members of the Executive Committee. The recommendations of the working party were accepted enthusiastically by the Trustees and Executive Committee and after a call for applications the membership elected Christopher Winearls as the first Renal Association Clinical Vice President from 2004, succeeded by Kevin Harris [Reader in Nephrology from Leicester] in 2007, and then Martin Raftery [Consultant Nephrologist from the Royal London Hospital] in 2010.

The success of these arrangements still did not dissipate sufficiently the increasing burden of work on the RA President. John Feehally, on succeeding Andy Rees as President, therefore initiated an equivalent discussion in 2004 about the co-ordination of Renal Association involvement in academic matters including education, training and research through an Academic Affairs Working Party chaired by Caroline Savage [Professor of Nephrology from Birmingham]. This required responses to the rapidly changing NHS R&D environment: the increasing pressure on academic medicine and the Renal Association's growing educational programmes. An Education & Research Board, soon renamed the Academic Affairs Board, was established to include the Chairs of the Education & Training Committee, Research Committee, Clinical Trials Committee, and International Committee, as well as two elected members of the Executive Committee. The Academic Affairs Board was initially chaired by the President, but a decision to appoint an Academic Vice President was soon made. The first Academic Vice President, Caroline Savage was elected in 2007.

This newly established Renal Association committee structure (Figure 6) has proved its worth ensuring an authoritative voice for RA over the full range of clinical and academic affairs.

Figure 5: Committee Structure Diagram



The chairs of all RA boards and committees since 2001 are shown in **Table 2.**

Table 2: Renal Association Committee Chairs 2001-2010

	Registry	Clinical Services^	Clinical Practice Guidelines+	Research	Education & Training	Clinical Trials	International
2001	Terry Feest	John Scoble	Alison Macleod	John Savill*	John Savill*	Peter Mathieson	
2002							
2003		Stuart Rodger		Caroline Savage*	Caroline Savage*	David Jayne	
2004			David Wheeler	Caroline Savage	Edwina Brown		Meguid El-Nahas
2005							
2006	Charlie Tomson	Kevin Harris					
2007			Robert Mactier				
2008		Martin Raftery		Bruce Hendry	Susan Carr	Colin Baigent	Jo Adu
2009							Albert Ong
2010	Damian Fogarty						

^ Clinical Services Committee known as Service Provision & Delivery Committee until 2004

+ Clinical Practice Guidelines Committee known as Standards & Audit Committee until 2006

* Research, Education & Training were covered by a single committee until 2004

The new structure also created responsibilities for the Immediate Past President, who until then had continued as a trustee for two years after completing the term as President but had no other specific tasks. The Immediate Past-President currently remains a trustee for three years; from 2010 this term will be two years to match the shorter term of office for the President. The Immediate Past-President chairs the Renal Registry Management Board [see below, Registry, page 21] and also chairs the RCP London/Renal Association Joint Specialty Committee for Renal Medicine [see below, RCP, page 26].

After debate, the Executive Committee decided that the President and the two Vice Presidents should remain the only officers of the Association elected by the entire membership. After inviting applications from the membership, the offices of Secretary and Treasurer, as well as Committee Chairs are appointed by a committee of the Trustees assisted by three elected members of the Executive Committee selected by the President.

Trustees

The increase in the number of elected and appointed officers of the Association led to a review of those officers who should also be trustees. In 2007 it was agreed that the Association's trustees should be:

President, Immediate Past President, President Elect (for one year before becoming President), Clinical Vice President, Academic Vice President, Secretary, Treasurer, Chair of the Registry Committee. In 2010 the BAPN President also became a trustee.

These various changes required a major overhaul of the Memorandum, Articles and Rules of Association, which was undertaken by Andy Rees, Adrian Woolf, John Feehally, and David Goldsmith and ratified in stages at the Association's Annual General Meetings in 2005, 2008 & 2009.

Membership

The Renal Association membership has grown continually between 2000 and 2010. Total membership has nearly doubled in this last decade: 648 in 1990, passing 1000 members in 2008, and reaching 1041 early in 2010. The Association continues to have among its members 95% of all consultant nephrologists in the UK so some of this membership growth was expected given that the number of consultants has grown from approximately 250 to 450 during the decade.

There has also been a growth in the number of nephrology specialist registrars who joined the Association but disappointingly this is still only 27% of all clinical trainees in the specialty. The Renal Association recognised importance of the contribution made by non-consultant career grade nephrologists, especially in dialysis units. A survey of units to identify all such doctors undertaken in 2005 by the Clinical Services Committee was followed by a representative of the Nephrology SAS [Staff Grade & Associate Specialists] Forum joining the Executive Committee. A growing number of renal laboratory scientists (i.e. those active in renal research without a medical qualification) have also joined the Renal Association, and the particular membership needs of this important group have been promoted through the election of one non-clinician scientist as a member of the RA Executive Committee. Since 2001 this position has been held successively by Paul Brenchley [Manchester], Alice Smith [Leicester], Tim Johnson [Sheffield], and John Reynolds [London]. Registration fees for Renal Association meetings have been adjusted for young scientists and scientific sessions focusing particularly on their interests and needs have become a standard feature of conference programmes.

Communication with the Renal Association's membership has been transformed and enhanced over the decade. At one time a posted letter from the Honorary Secretary and President every few months was all that a Renal Association member might expect to receive. Now monthly news distributed by email is the norm, the Association's website has

become a widely used, easily navigable source of information about the Renal Association and issues of relevance to its membership over a wide clinical and academic range. The website was first established by Stephen Powis [London] and later flourished under the direction of Neil Turner [Edinburgh], website manager until 2007). He was succeeded by Mark McGregor [Kilmarnock], and supported by the addition of Saeed Ahmed [Sunderland] as Deputy Website Manager from 2009. However, the routine maintenance and updating of the website has exceeded the capacity of even these enthusiastic nephrologists so from 2010 MCI has managed many routine aspects of website maintenance. From 2009 all the Association's elections have also been undertaken electronically.

Corporate Members

The decision for the Renal Association to create corporate membership was controversial when first taken in 1995. Corporate membership is now an established part of the Association's structure and as well as being valuable for its financial health, has provided many other benefits. The Renal Association has sought working relationships with companies engaged in the renal field, and the number of corporate members has grown steadily to 10 in 2010. Corporate members pay an annual membership fee, for 2010 the fee has been reviewed and is currently £5,000. Corporate members are given a one to one opportunity to meet with one or more Renal Association Trustees on an annual basis, have an annual group meeting with the Trustees to discuss mutual interests, and meet regularly over breakfast during the Annual Conference. The mutual benefits for the Association and its corporate members are now well recognised and the clearly established lines which demarcate an appropriate partnership from inappropriate commercial interest are well respected.

Finances

The decade was characterised by the soundness of the Association's finances and the gradual growth of reserves sufficient to support the rising running costs for both the Renal Association and the Renal Registry for at least a year. Stepped increases in individual and corporate membership fees were little different overall from inflation but combined with modest profits from most annual conferences, and the growing number of members, the Association has been able to fund and subsidise smaller meetings and other educational programmes, and to absorb substantial new costs such as those required to develop the Specialty Certificate Examination in partnership with The Medical Royal Colleges.

The UK Renal Registry remains part of the Renal Association for accounting and charitable law purposes. The acceptance of capitation based funding gave the Registry financial stability which has protected the Renal Association's overall finances. It has also

enabled the reimbursement of time (in 2010 three 'programmed activities' per week[3]) to the organisation which employs the Registry Chair [all other Renal Association officers have remained unpaid volunteers and still have to deliver their responsibilities within their own time]. It has also been possible to expand the Registry staff to meet the increasing workload [see below, Registry]

Renal Association Annual Conference

Popular and well attended meetings which are scientifically, educationally and socially effective remain fundamental to the Renal Association's *raison d'etre*. In 2000 the pattern of meetings had changed little since the mid-1980s. Two meetings a year - a Spring Meeting outside London and an Autumn Meeting in London [recently meeting at the Royal College of Physicians] - was the standard pattern.

In 2004 Renal Association members were again invited to comment on a proposal for a move to a single annual conference. The majority indicated a preference for this change to provide a high quality meeting with a strong scientific programme, and excellent national and international faculties, which also makes best use of the limited study leave allowances available to most members. The Executive Committee therefore resolved that from 2005 a single annual meeting would be held.

At the same time discussions began about the possibility of joint meetings. These had happened occasionally in the past (for example, joint meetings with the Dutch Society of Nephrology in Amsterdam in 1989, and in Oxford in 1996). In 2002, a joint meeting was held with Harvard Medical School, USA, which was not entirely successful, not least because not all the invited Harvard faculty were eventually able to attend the meeting. However in 2003 a very successful Autumn London meeting was held jointly with the Mayo Clinic, USA

Proposals for joint meetings with related UK organisations were also explored, and although the initial conferences were planned with some trepidation, they proved an unequivocal success. The first joint meeting with the British Transplantation Society, in Belfast in 2005, was repeated in Liverpool 2009. A first joint meeting with the British Renal Society in Harrogate 2006, was repeated in Glasgow 2008, and again in Manchester 2010. Although such meetings present a considerable challenge to the Scientific Programme Committee to provide a programme catering for the interests and needs of diverse professional groups, they have been judged as having a consistently high scientific standard and enhanced by the vibrancy associated with a larger meeting. In terms of scope and attendance, the Renal Association Annual Conferences have grown remarkably in the last decade It seems likely that both the decision to have a single annual conference, and the

[3] A 'programmed activity' [PA] is the 'currency' in 2010 in which NHS consultant time is measured. 1 PA is broadly equivalent to half a working day.

move to joint meetings, are contributing to that growth. **Table 3** shows various markers of success of the Annual Conference since 2001.

Table 3: Renal Association Annual Meetings 2001-2010

	Venues	Partners	Number of registrants	Number of abstracts
2001	Nottingham & London		392	234
2002	York & London	Harvard Medical School [autumn London meeting]	493	329
2003	Keele & London	Mayo Clinic [autumn London meeting]	404	187
2004	Aberdeen & London	-	391	218
2005	Belfast	BTS*	300[4]	366
2006	Harrogate	BRS^	1,181	354
2007	Brighton	-	430	244
2008	Glasgow	BRS, SRA"	1,300	412
2009	Liverpool	BTS	1,073	531
2010	Manchester	BRS	1,119	462

* British Renal Society
^ British Transplantation Society
" Scottish Renal Association

The organisational and financial arrangements for joint meetings have required substantial work behind the scenes especially for the Renal Association's President, Treasurer, Secretary, and secretariat. A different budgetary model and registration fee structure had to be found which met the varying needs of the societies involved. In the case of a joint conference with the BRS (which is not a fee-paying membership society) the financial models are necessarily unusual. Nevertheless joint meetings will continue and it remains a matter for debate both within the Renal Association and with potential partners whether such joint meetings should become routine to help the UK wide renal community to grow together, to take advantage of the economies of scale they offer, and to eke out the restricted commercial sponsorship for such meetings which is likely be available in the future.

The Annual Conference continues to provide the occasion for the Association's long established Osman and Chandos Lectures[5], and from 2007 the newly established de Wardener Lecture.[6] Named Renal Association Lecturers since 2001 are shown in **Table 4.**

[4] BRS members not included in total; Overall attendance estimated at 500 plus
[5] For more about the origins of the Osman and Chandos lectures and lecturers before 2000, see http://www.renal.org.educationtraining/Lectures
[6] The de Wardener Lecturer was originally established in 2005 by Professor Hugh de Wardener's former colleagues at Charing Cross Hospital, Graham MacGregor and Edwina Brown. de Wardener himself gave the inaugural lecture in his ninetieth year, a sparkling exposition of his career long interest in renal sodium handling

Table 4: Renal Association Named Lecturers 2001-2010

	Osman	Chandos	de Wardener
2001	Norbert Lameire [Belgium] Disaster Nephrology	*No lecturer appointed*	-
2002	*No lecturer appointed*	Peter Ratcliffe [UK] Oxygen sensing	-
2003	Jeffrey Platt [USA] New insights into autoimmunity	*No lecturer appointed*	-
2004	*No lecturer appointed*	Ram Gokal [UK] Peritoneal dialysis	-
2005	*No lecturer appointed*	*No lecturer appointed*	-
2006	Peter Mathieson [UK] Understanding focal segmental glomerulosclerosis	*No lecturer appointed*	Bryan Williams [UK] The hypertensive heart*
2007	*No lecturer appointed*	Steven Harper [UK] How the glomerulus works in health and disease - or so you thought	Pierre Ronco [France] New insights into the pathophysiology of membranous nephropathy: a bench-to-bedside story
2008	Juergen Floege [Germany] From cage to bedside: new approaches to the treatment of CKD patients	*No lecturer appointed*	Richard J Johnson [USA] Uric acid, the metabolic syndrome and kidney disease
2009	Andy Rees [Austria]	Dontscho Kerjaschki [Austria]	Tim Goodship [UK] Haemolytic Uraemic Syndrome
2010	David Salant [USA] The antigenic target in membranous nephropathy	Rob Horne [UK] Supporting behaviour changes in patients with chronic kidney disease	Barry Freedman [USA] New genetic insights in end-stage renal disease

* Lecture given at the RCP –Renal Association- British Hypertension Society Meeting at RCP London

and hypertension. At the request of Brown and Macgregor, the Renal Association took the de Wardener lectureship into its portfolio from 2006.

In addition to the named lectures of the Renal Association major national and international figures were increasingly invited as speakers to the Renal Association Annual Conference; for the 2010 Conference in Manchester, there were 9 invited speakers from overseas.

As well as the Annual Conference increasingly becoming a joint event, opportunities have been taken to develop smaller [usually one day] on specific topics, sometimes organised jointly with other societies both within and beyond the UK (**Table 5**).

Table 5: Joint scientific meetings with other organisations 2001-2010

Date	Meeting title	Partner organisation[s]	Venue	Named Lecture
2005	End of Life Issues in Renal Medicine: are we facing up to the challenges?	RCP London	RCP London	RCP Osler Lecture Christopher Winearls In the wake of progress – ethics in renal failure
2005	Facing an epidemic of CKD	RCP London	RCP London	RCP Teale Lecture Robert Postlethwaite Improving care of children with chronic kidney disease
2005	Proteinuria	RSM**	RSM	
2006	Hypertension and the Kidney	RCP London, British Hypertension Society		de Wardener Lecture Bryan Williams The hypertensive heart
2007	CKD Consensus	RCP Edinburgh	RCP Edinburgh	
2007	Clinical Challenges in Nephrology and Haematology	RCP London, British Society for Haematology	RCP London	RCP Sir Michael Perrin Guenter Weiss [Austria] Anaemia and inflammation
2008		RSM Société de Nephrologie	RSM	
2009	Chronic Kidney Disease	RCP London	RCP London	RCP Watson Smith Lecture Adeera Levin [Canada] The disparity between evidence and guideline-based practice: CKD the c state
2009	Optimising Care at the Cardio-renal Interface	RCP London British Cardiorenal Forum British Cardiovascular Society	RCP London	

* Royal College of Physicians of London; ** Royal Society of Medicine

Clinical Affairs

The establishment of a Clinical Affairs Board was undoubtedly justified by the increasing range and complexity of work with which the Association needed to engage to ensure the voice of nephrology received due emphasis in the rapidly changing NHS.

Clinical Services

The decade saw little change in the number of renal units in the UK, but nevertheless was characterised by rapid changes in the organisation and delivery of clinical renal services. The case for a Clinical Services & Delivery Committee was first made to the Renal Association by John Scoble [Guy's Hospital, London] who became its first chair in 2001. Renamed as the Service Provision & Delivery Committee, and most recently the Clinical Services Committee, its membership has regional representation to ensure varying perspectives are recognised. Scoble also established a very popular Clinical Director's Forum [held each March in London] which has ensured clinical directors are kept abreast of major developments and have an opportunity to feedback to the Association the major issues they are confronting.

The Kidney Alliance (an umbrella lobbying organisation for the renal community of which the Renal Association is a member) led the way in convincing the Department of Health in England that a National Service Framework [NSF] was required for renal services because of the increasing overall cost to the NHS of renal replacement therapy with the continuing increase in the number of patients being treated. Another part of the case for a National Service Framework was the emerging evidence that less severe forms of chronic kidney disease were common, and that early identification and effective management gave opportunities to delay or prevent ESRD, as well as identify a population at high cardiovascular risk. The established roles of the Renal Association Standards documents [setting standards of care] and the UK Renal Registry [auditing achievement of those goals] were key elements in the case being made for an NSF. The publication of the NSF in two parts in 2004 and 2005 was followed by an equivalent document for Wales published in 2007 as well as continuing reviews of clinical service delivery in Scotland and Northern Ireland.

The Department of Health in England sought to oversee the implementation of the NSF by appointing a Renal Advisory Group whose second Chair, Donal O'Donoghue, in 2007 became the first National Clinical Director for Kidney Care for England. Although the Renal Association was not formally represented on the Renal Advisory Group, or among the expert groups which developed the NSF, senior Renal Association members played key roles at all stages. Implementation of the NSF thereafter coincided with a substantial expansion of haemodialysis facilities which has begun to redress the problem of insufficient resources for the treatment of patients with end-stage renal disease. The issue of an

expansion in home haemodialysis which had been proposed in NICE Guidance[7] has also been examined. The estimates made by NICE of the proportion of dialysis likely to choose home haemodialysis, and be suitable for it, are deemed by the majority to be unrealistic, and the preferred approach is to give patients choice by ensuring that all modalities of renal replacement therapy are widely available. In 2010 the Renal Association has published guidance on how the use of this modality can be maximised[8].

One government strategy for expanding haemodialysis capacity promoted from 2005 was the development of independent sector treatment centres [ISTCs]; this proved controversial. Although privately run satellite haemodialysis units within the coherent governance framework of 'parent' NHS units had become an accepted way to expand capacity since the 1980s, the Renal Association expressed its concerns that the new ISTCs should not take provision beyond that familiar and coherent structure. The ISTC programme was not perpetuated after a single round of such centres were commissioned in the north of England in 2008.

At the same time the Renal Association has played a key role in influencing the impact of a new understanding of the earlier stages of chronic kidney disease [CKD]. The decade saw its emergence as a recognised cardiovascular risk factor requiring attention and intervention in primary care. This also provided an opportunity to increase early detection of the minority with CKD who have progressive kidney disease, and who are particular risk of poor outcomes if referred late to renal units. The introduction of CKD parameters in the Quality and Outcomes Framework by which general practitioners in England are rewarded, the need to educate GPs about the meaning of estimated GFR [reported routinely by all UK laboratories from 2006] and proteinuria, and the need to help Renal Association members manage the transient rise in referrals for specialist nephrology opinion have all fallen to the Renal Association through its Clinical Services Committee and Clinical Affairs Board. It was recognised that the very rapid implementation of these changes, necessarily opportunistic, should lead to improvement in the care of patients with CKD. The acceptance rate onto RRT has stabilised at ~110 pmp[9] for the last three years of the decade, and there is some suggestion that the number of 'crash lander' patients making unplanned starts on RRT may be reducing; although direct attribution of 'cause and effect' is not yet clear.

Guidelines on the early detection, and management of CKD produced by a working party of the Joint Specialty Committee of the Renal Association and the Royal College of Physicians and other relevant professional organisations were published in 2006[10]. .

[7] NICE Guidance on home compared to hospital haemodialysis for patients with end-stage renal failure. October 2002. http://guidance.nice.org.uk/TA48/Guidance
[8] Renal Association Working Party on Home Haemodialysis
[9] per million population

[10] Chronic kidney disease in adults - UK guidelines for identification, management and referral. http://www.rcplondon.ac.uk/pubs/books/kidney/

Subsequently, the National Collaborating Centre for Chronic Conditions [NCC-CC] worked with NICE to develop guidance on CKD, which in due course superceded the Renal Association document and was published as a National Clinical Guideline[11]. The Renal Association made representations to NCC-CC on behalf of the membership expressing both support and concerns about the NKF-KDOQI Classification of CKD which had been adopted in the UK. Members of the Association invited to join the guideline development group included Paul Stevens [Canterbury] [co-chair], Lawrence Goldberg [Brighton], Kevin Harris, Ian John [Canterbury], Edmund Lamb [Canterbury], Natasha McIntyre [Derby], and Paul Roderick [Southampton].

In 2009 the preparation of policies for the management of pandemic flu were led by the Royal College of Physicians but again required major Renal Association input through the JSC represented by Lawrence Goldberg to ensure sensible and pragmatic advice which did not disadvantage patients with kidney disease.

The Clinical Affairs Board has also directed a number of working parties established jointly with other organisations to make recommendations on the organisation of care for aspects of renal replacement therapy, and has contributed to such groups initiated by others. These have included working parties on vascular access, peritoneal dialysis access, home haemodialysis, peritoneal dialysis, haematuria, and fluid management in surgical patients [Table 7].

The Renal Association submitted the proposals which led to both NCEPOD[12] and SASM[13] undertaking enquires which highlighted the suboptimal care given to many patients with acute kidney injury during emergency admissions to hospital[14]. The well publicised results of the NCEPOD Acute Kidney Injury: Adding Insult to Injury (2009) gave the Association the opportunity, with the Royal Colleges and NHS Kidney Care, to promote improvements in care in this often neglected area of nephrology.

Table 7:

Involvement of the Renal Association in working parties and guideline groups 2001-2010

Date published	Name	Partners	RA lead
2006	Vascular Access Working Party Report	Vascular Society of GB & Ireland British Society for Interventional	Christopher Winearls Richard Fluck

[11] NICE Guidance. Early identification and management of chronic kidney disease in adults in primary and secondary care.. http://guidance.nice.org.uk/CG73
[12] National Confidential Enquiry into Patient Outcome and Death
[13] Scottish Audit of Surgical Mortality
[14] http://www.ncepod.org.uk/2009aki.htm

		Radiology	
2007	The Changing Face of Renal Medicine in the UK	RCP London	Gordon Bell John Feehally Tim Goodship Paul Rylance
2008	Peritoneal Dialysis Access Working Party Report		Martin Wilkie
2008	RA-BAUS Haematuria Consensus Guidelines	British Association of Urological Surgeons	Lawrence Goldberg Robert Mactier John Feehally
2009	British consensus guidelines on Intravenous fluid therapy for adult surgical patients	British Association for Parenteral and Enteral Nutrition Association for Clinical Biochemistry Association of Surgeons of GB & Ireland Society of Academic & Research Surgery Intensive Care Society	Andrew Lewington
2009	Helping Adolescents & Young Adults with ESRF	BAPN	John Feehally with David Milford [BAPN]
2009	PD Working Party Report		Edwina Brown
2010	Home Hemodialysis Working Party Report		Robert Mactier Sandip Mitra
2010	Rare Kidney Diseases: an integrated strategy for patients in the UK	BAPN	John Feehally with Mark Taylor [BAPN]

Clinical Practice Guidelines

The Renal Association was one of the first national societies to appreciate the importance of developing clinical standards against which quality of care could be audited locally and also nationally through the Renal Registry. The 3rd edition of Renal Association Standards [2002] was published, like its predecessors, as a bound paper document published by RCP London[15], prepared by the Renal Association Standards Committee, chaired by Alison Macleod [Aberdeen]. It became clear that the same process could not be used in future since it was increasingly difficult to keep a very large document up-to-date with emerging clinical evidence. Under the successive chairmanship of David Wheeler [London] from 2004-2007, and Robert Mactier [Glasgow] from 2007, the renamed RA Clinical Practice Guidelines Committee was charged with developing the guidelines in electronic 'modular' format, each chapter being available on the Renal Association website and "locked" with agreed review dates. Renal Association members [with expertise but without commercial conflict] were designated as leads for each chapter and a continuing turnover of the leads

[15] Renal Association. Treatment of adults and children with renal failure: standards and audit measures. 3rd Edition. London: Royal College of Physicians of London and the Renal Association, 2002

ensured freshness and energy. The Renal Association along with the equivalent guideline groups in Canada and Australia are the three national societies as well as the European Best Practice Guideline Group whose guidelines are recognised and tabulated by the international leaders in this field – the Kidney Disease Improving Global Outcomes (KDIGO).

UK Renal Registry

The UK Renal Registry began the decade determined to reach its first goal of achieving complete UK wide electronic data collection on 100% of patients receiving RRT. Under the founding chairmanship of Terry Feest [Bristol] with David Ansell as Registry Director, this goal was achieved in 2009 and the Registry's reputation nationally and internationally continued to grow. The Registry's Reports were seen as authoritative, and a crucial source of data for the NHS and the Department of Health. However its progressive costs, growing staff requirements, and increasing complexity as it took on outside research projects, required a new organisational model. The Renal Association Trustees had always been responsible for the affairs of the Registry but this was now formalised during the presidency of Andy Rees by the creation in 2003 of a Renal Registry Management Board consisting of the Renal Association Trustees with the Registry Chair, Registry Director (and later the Registry Manager and Deputy Director). This group meets quarterly under the chairmanship of the Immediate Past President and has successfully secured the financial and organisational governance of the Registry. In 2006 Terry Feest retired as Chair after an extremely successful ten year tenure which had seen the original vision, for the Registry, first developed during the Presidency of Netar Mallick, come close to completion. He was replaced by Charlie Tomson (2006-2010), and then Damian Fogarty [Belfast] (2010-). Data collection on all adult patients in the UK receiving RRT was achieved in 2009. Gradual integration with the previously free-standing paediatric registry continued; by 2010 electronic returns had been achieved from about half of paediatric units, and delays in other units were due to factors beyond the immediate control of the Registry or the Renal Association, usually due to insufficient investment by hospital IT departments in the necessary systems.

During the decade the Registry has achieved earlier publication of its Annual Report and moved from a paper report to on-line publication through the journal Nephron Clinical Practice which ensured the Registry Report appeared on PubMed. There are plans to expand the role of the Registry as a tool for continuous quality improvement, and in research. The international reputation of the Registry is high and its major product, the Annual Report, is much valued by those who commission RRT, and the renal units which deliver it. It is moreover unique among renal registries around the world in that audit data from individual units are no longer anonymised.

Unlike equivalent registries in other specialties, the UK Renal Registry maintains its independence from NHS and the Department of Health and by establishing payment from each renal unit by capitation has ensured its financial stability and future.

In 2009 the Registry and the Renal Association absorbed the organisation and management of *RenalPatientView*, the award winning web-based system which allows direct access for patients to their clinical information held in renal unit information systems. *RenalPatientView*, the first patient-centred web-based access of its kind was developed by a group of Renal Association members led by Neil Turner [Edinburgh] and Keith Simpson [Glasgow]. Established with an initial grant from the Department of Health, it has from 2008 also been funded by capitation. In 2009 discussions began to explore the establishment of a registry for rare renal diseases within the main Renal Registry.

'Green' Nephrology

In 2009, in response to a challenge to the Renal Association by Sir Muir Gray on behalf of the Campaign for Greener Healthcare, it began to support work on reducing the carbon footprint of renal medicine. In partnership with the British Renal Society, with funding from NHS Kidney Care (an organisation whose main purpose is support quality improvement in kidney care as part of implementation of the National Service Framework), a Green Nephrology specialist registrar, Andrew Connor, was recruited. The Renal Association has adopted a sustainability policy, committing itself to a reduction in carbon output as a result of its activities.

Academic Affairs

Education and Training

At the beginning of the decade a single Renal Association committee, chaired by John [now Sir John] Savill [Edinburgh] covered research, education and training. The

increasing demands in all these sectors led to the establishment of a separate Education and Training Committee, first chaired by Edwina Brown [Imperial College, London] from 2004, then Susan Carr [Leicester] from 2008.

The Renal Association has continued to give priority to providing opportunities for high quality education for all its members. Continuous Medical Education [CME] programmes are now a regular feature of the annual conference and include elements designed for non-clinical scientists. The Advanced Nephrology Course has also blossomed during this decade under the successive leadership of Charlie Tomson, Megan Griffith [London], Alex Crowe [Chester], Mark Harber [Royal Free Hospital, London], and from 2009 Sunil Bhandari [Hull] and Paul Harden [Oxford]. It has been so successful that it is now delivered twice a year at different venues in order to provide sufficient places for demand, and covering the whole training curriculum over a four-year period. The majority of attendees continue to be specialist registrars so the programmes are designed to cover the specialist training curriculum, but are also suitable for consultant CME.

From 2005 onwards RA has also offered one to two one-day conferences on more specific topics [see above, Meetings].

In 2010, the Renal Association also broke new ground in its educational programmes by securing in partnership with the Royal College of Physicians funding from the Department of Health to establish an E-learning for Health project in renal medicine. The development of this resource for those in core medical training as well as specialty training will be led by Sue Carr and John Firth [Cambridge].

The Renal Association has worked closely with the Specialist Advisory Committee for Renal Medicine of the Royal College of Physicians of London as the requirements for specialist training and its appraisal have continuously evolved throughout the decade. In 2009-10 the, Susan Carr [Chair of the Education & Training Committee] chaired a Curriculum Review Group to provide a thorough re-appraisal of the long established training curriculum. A major aspect of changing appraisal for trainees was the introduction in 2009 of a Specialist Certificate Examination [SCE], a knowledge-based assessment designed to be taken in mid training as one element of a complete appraisal of both the knowledge and practical skills of the trainee. The SCE was developed as a partnership by the Royal Colleges of Physicians with specialist societies, the Renal Association being responsible for question setting, the College providing the organisational infrastructure. Thanks to the energy of Renal Association members, led by Jonathan Fox [Glasgow] the SCE in Renal Medicine was one of the first examinations available, candidates sitting it for the first time in March 2009. Discussions between the Colleges and the specialist societies about the financial and organisational governance of the SCE, led for the Association by the President and Treasurer, proved “tense and challenging”. They were however to provide a stimulus to

closer working between the various professional societies in internal medicine whose Presidents began to meet regularly from 2008 in a more formal coalition of Medical Specialty Societies to discuss a wide range of service and training issues of mutual interest.

Research

Despite the increasing range of clinical service and educational issues with which the Renal Association has become involved, it has never wavered in its commitment to promoting research into the kidney and its diseases in the UK. The Renal Association Conference has always been an ideal platform for investigators to present their work to the national renal community. The Renal Association has continued to work closely with Kidney Research UK (KRUK); which during the decade changed its name from National Kidney Research Fund which had actually been launched in 1966 by members of the Renal Association. The success of Kidney Research UK as a funder and promoter of renal research is obvious at the Renal Association Conference when past and present KRUK Fellows are regular presenters in the plenary sessions of best submitted abstracts, and where the KRUK logo is regularly prominent when acknowledgements are given of financial support at the end of free communications and invited lectures.

The Research Committee was separated from the previous Research Education & Training Committee in 2004; it was first chaired by Caroline Savage and since 2008 by Bruce Hendry [London]. The Committee has worked in a decade which has seen an accelerating pace of change in the structure and organisation of R&D in the NHS to which the Renal Association needed to respond if opportunities were to be taken. While the national NHS structures were still emerging, the Renal Association took the initiative with KRUK to establish a UK Kidney Research Consortium with other partners including BAPN, BRS and BTS. The Consortium cut its teeth by establishing clinical specialty groups which began to discuss the potential for national clinical trials in nephrology, an area where regrettably the renal community has consistently lagged behind many other specialty groups. NHS structures were then established with local Comprehensive Research Networks and national speciality networks. Caroline Savage, Academic Vice President of the Renal Association, was also appointed national renal lead. In 16 of 20 local Comprehensive Research Networks in England nephrology was identified as a research priority, and Renal Association members became local specialty leads. At the end of the decade it was still unclear how these new structures would facilitate research but the Renal Association had ensured it was positioned to make the best of any opportunities. The Renal Association's Research Committee continued to have representation from academic nephrologists, research active NHS nephrologists, and non-clinical scientists. The Committee worked to understand and embed renal research within the emerging NHS R&D programmes. In 2009 the Committee

developed an initiative to better integrate the wide range of renal genetics research in the UK holding a very successful workshop where issues related to both monogenic and complex polygenic disorders were debated by those in the field.

Through its Raine Award, the Association has continued to recognise research excellence among its members. Established in memory of Tony Raine, Professor of Renal Medicine at St Bartholomew's Hospital, London following his tragically early death in 1995, this prestigious annual award is made to a young investigator (usually 35 years of age or less) who has made a significant contribution to renal research. The Raine Award has continued to highlight the world class science of Renal Association members, and five of ten awardees in this decade have been women (Table 8). The recipient gives a lecture at the Renal Association Annual Conference in the year of the award.

Table 8: Renal Association Raine Award 2001-2010

2001	Coralie Bingham	Definition of the renal cysts and diabetes syndrome
2002	Sally Feather	Genetic basis of foetal malformations of the kidney and urinary tract
2003	Helen Lachman	Amyloidosis
2004	Jeremy Duffield	The role of macrophages in renal inflammation
2005	Anna Richards	Atypical haemolytic uraemic syndrome
2006	Menna Clatworthy	Immune inhibition
2007	John Sayer	Molecular genetics of nephronophthisis
2008	Bryan Conway	Finding genes for diabetic kidney disease
2009	David Kavanagh	The pathogenesis of haemolytic uraemic syndrome
2010	Andrew Salmon	Regulation of glomerular permeability

Clinical Trials

The Renal Association Clinical Trials Committee was chaired by Peter Mathieson, succeeded in 2003 by David Jayne [Cambridge], and then in 2008 by Colin Baigent [Oxford]. It has provided critical review of protocols offered by those seeking to conduct clinical trials in the UK. Typically such trials would go on to seek pilot funding from KRUK and an agreement emerged with the Grants Committee of KRUK that it would be expected that any such trial would have had been reviewed by the Renal Association Clinical Trials Committee before being considered for funding. The emergence of the UK Kidney Research Consortium and

the associated Clinical Specialist Groups, has provided additional opportunities for the Clinical Trials Committee to develop more ambitious projects.

International Committee

The Renal Association International Committee is the most recent of the Association's Committees, formed in 2004 on the recommendation of Andy Rees. It was first chaired by Meguid El-Nahas [Sheffield], succeeded by Dwomoa [Jo] Adu [Birmingham] from 2008, then from 2009 by Albert Ong [Sheffield]. It was formed to strengthen the Association's links with the International Society of Nephrology [ISN] and to promote the UK contribution to nephrology in the developing world. A number of Renal Association members had been contributing over the previous decade or so – by hosting overseas fellows [through the ISN and other funding], by building relationships with emerging renal units in the developing world [both through the ISN Sister Renal Centre Programme, and other means]. The growing emphasis of ISN on such work, the UK's unique position because English is the international medical language, and the continuing worldwide respect for UK training, all provided cogent reasons for the Renal Association to "punch above its weight" as a contributor to nephrology in the developing world. This international reputation was built on foundations laid by former Presidents of the Association, Stewart Cameron and David Kerr who were ambassadors for UK nephrology especially in developing countries. Furthermore throughout this decade members of the Renal Association were playing an increasingly prominent role in ISN leadership: Andy Rees [ISN Councillor 1997-2003, Executive Committee 2001-2003]; John Feehally [ISN Councillor 2003-09, Secretary General 2005-09, President Elect 2009-2011]; Meguid El Nahas [ISN Councillor 2009-]; Paul Harden [Chair ISN Sister Centre Programme 2009-].

To a lesser extent, the Renal Association continued also to maintain links with the European Renal Association, at one time in the decade [2005-08] having among its members two ERA Councillors, David Goldsmith & Iain Macdougall [King's College Hospital, London].

<u>Interactions with other societies and organisations</u>

RCP London

As the Renal Association increased in size and influence during the 1990s, its role as a specialist society began to overlap the traditional roles of the Royal College of Physicians [RCP] of London. Both had active interests in education, training, and the setting of standards of clinical care. The RCP London/Renal Association Joint Specialty Committee [JSC] for Renal Medicine met regularly but there was concern that its agenda and that of the Renal Association Executive Committee were often very similar. Andy Rees was JSC chair up to 2001 before he became RA President and he streamlined the JSC membership to

ensure other renal organisations were represented, and to refine the agenda. When John Feehally became JSC Chair in 2007, he reached an explicit understanding with the RCP London that the goals of the JSC were “to ensure that the College is properly briefed on issues in the specialty and the Renal Association is briefed on College plans and policy.” The focus of the Committee was to be on issues in which the RCP could use its influence to achieve more than could be achieved by the Renal Association acting alone; some of these would be specialty specific, others were generic. It was also agreed that the JSC Chair would always be the Renal Association’s Immediate Past President, helping to ensure informed continuity.

The JSC, during John Feehally’s chairmanship, gained approval from the RCP Council to create a working party [chaired by John Monson [London]] to report on 'The changing face of renal medicine in the UK: the future of the specialty'. Published in 2007, the working party report laid out many of the challenges in service development, workforce, education and training confronting the specialty.

BRS

The British Renal Society [BRS] was established to represent the whole multiprofessional renal team evolving from the British Renal Symposium, an annual meeting started in 1989 which focused on research and education in the care of patients with kidney disease. The BRS is not a membership organisation but a federation of the various professional groups representing those in involved in renal care. The interests of these groups would not have been catered for in the Renal Association meetings of the time which contained a heavy emphasis on the scientific basis of kidney function and disease. Since the clinical goals of the BRS and Renal Association are completely aligned, it is perhaps unfortunate that they became two separate rather than sister organisations. In retrospect it appears that this could have been avoided if there had been greater flexibility and trust in the 1990s between those championing the emerging BRS, and those leading the Renal Association.

During the last few years, there has been increasing co-operation between the Renal Association and the BRS, exemplified by the successful joint conferences. The RA President has become an *ex officio* member of the BRS Council and the BRS President sits *ex officio* on the Renal Association Executive Committee.

BTS

The British Transplantation Society represents those involved in all organ transplantation in the UK, not only kidney transplantation. Many Renal Association members are actively involved in clinical and academic aspects of kidney transplantation, and are also

members of BTS. The shared goals of progress in transplantation have led to increasingly close working in the last decade between the Renal Association and the BTS exemplified by the successful joint conferences in 2005 and 2009.

BAPN

The British Association for Paediatric Nephrology [BAPN] was founded in 1973 providing an important and distinctive voice for paediatric nephrology in the UK. Its small membership may have limited the extent of its influence in clinical service development as well as education and training. The last decade has seen increasingly close working relationships between BAPN and the Renal Association particularly during the BAPN Presidency of Mark Taylor (2006-2009). He led discussions within BAPN which resulted in 2009 in acceptance of the proposal that BAPN cease to be an independent entity but become a "chapter" of the Renal Association, an arrangement formalised in January 2010; the BAPN President, now Mary McGraw [Bristol] , has become a Trustee of the Renal Association. Taylor had worked with two successive Renal Association Presidents, Feehally and Mathieson, to take other opportunities to strengthen the partnership between paediatric and adult nephrology in the UK. These very successful initiatives had three main elements.

<u>ESPN 2009</u>

A joint BAPN and Renal Association bid was made to bring the European Society for Paediatric Nephrology biennial congress to Birmingham in September 2009. In an initiative unique to ESPN congresses, one day was devoted to a joint meeting with the Renal Association which focussed on diseases of the primary cilium and bought together a distinguished international faculty with expertise in both paediatric and adult cystic disease. This highlighted the benefits of adult and paediatric nephrology working together, which was the theme of Feehally's brief address given when he was representing the Renal Association at the Congress opening ceremony.

<u>Transition</u>

The challenges of transition of young adults from paediatric to adult care, especially those requiring renal replacement therapy, has been a point of weakness in renal services in the UK and other countries. It has always been known to be a period of uncertainty for such patients where risk taking behaviour may manifest itself, for example stopping immunosuppressive therapy or becoming intolerant of lifestyle restrictions associated with dialysis. Proponents of a need for structured transition to minimise such risks had until recently mostly come from paediatric nephrology. In 2008 a joint Renal Association BAPN working party to explore these issues was established, co-chaired by John Feehally and David Milford (consultant paediatric nephrologist, Birmingham). The working party included adult and paediatric nephrologists, clinical psychologists, nurse specialists, patients and carers. A Working Party Report, Helping Adolescents and Young Adults with ESRF was

agreed by both societies[16] and also endorsed by the respective Colleges. This report coincided with a commitment from NHS Kidney Care to improve the quality of care in the specific area of transition, by investing in schemes to test new models of care including those proposed by the working party.

Rare Diseases Strategy

In 2009, a further joint Renal Association BAPN working party was established, chaired by Mark Taylor and John Feehally, to develop a strategy for the management of rare renal diseases in the UK. The working group included adult and paediatric nephrologists, clinical geneticists, clinical biochemists, specialist nurse, clinical psychologist, patients, and representatives of the pharmaceutical industry with commitment to orphan diseases. The goals were not only to define appropriate care pathways but also to integrate this with a strategy for audit, research, training and education. A Rare Diseases Registry with sustainable funding and integrated into the UK Renal Registry is a key part of this initiative. The Working Party Report was published in 2010.

Conclusion

The Renal Association's sixth decade has been characterised by continuous and remarkable growth. The increase in the number of members was perhaps inevitable given the increasing number of nephrologists in the UK, but nevertheless it is satisfying that 95% of all consultant nephrologists are Renal Association members, that there has been a steady growth in the proportion of trainees who are RA members (although it is hoped this will increase) and that there has also been substantial growth in the number of non-clinical scientists active in renal research who have joined the Renal Association. There has also been major expansion and refinement in the organisation of the Association's structures and management; but not for its own sake, the Association's leadership being ever committed to ensuring that more committees and more structures have purpose in forwarding the goals of the Association.

The Renal Association has not changed its commitment to its core values and activities. The Renal Association conferences have changed to an annual format and often in partnership with other societies; the meetings are now unrecognisable from a decade ago in numbers of registrants, numbers of submitted abstracts, size and quality of invited faculty.

The Renal Association's clinical affairs structures have placed it in an ideal position to influence national policies for clinical renal service delivery and development. This has particularly been so in England with the appointment of the first National Clinical Director, who is a former President Elect of the Renal Association. Part of that influence has also

[16] RA BAPN Helping Adolescents and Young Adults with ESRF. http://www.renal.org/whatwedo/Publications.aspx

been provided by the sustained growth in reputation and broadening involvement of the UK Renal Registry.

In education and training the Association has positively influenced patterns of training evaluation, curriculum review, and the development of the Specialty Certificate Examination. As well as the educational value of the Annual Conference, the Association has built the reputation and expanded the position of the Advanced Nephrology Course and provided an increasing range of other educational opportunities both on line and in one-day, one-topic conferences.

In research the Association has continued to provide an ideal forum for presentation of new work at the Annual Conference and has integrated with a complex and emerging national R&D agenda.

It seems assured that the Association's seventh decade will be characterised by more expansion in size. Importantly though, the Association needs to ensure that its members and leaders are mobilised to grasp the many opportunities for the growth and enhancement of nephrology which will undoubtedly arise.