

THE RENAL
ASSOCIATION
founded 1950



ANNUAL REPORT

2012

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EXECUTIVE COMMITTEE OFFICERS AND TRUSTEES

TRUSTEES

President	Dr David Wheeler
Past President	Dr Charlie Tomson
Honorary Secretary	Dr Alison Brown
Honorary Treasurer	Dr Jonathan Fox
UK Renal Registry Chair	Dr Damian Fogarty
Academic Vice-President	Prof Bruce Hendry
Clinical Vice-President	Dr Martin Raftery
British Association of Paediatric Nephrology (BAPN) President	Dr Jane Tizard

EX OFFICIO

National Clinical Director for Kidney Care	Dr Donal O'Donoghue
Specialty Advisory Committee (SAC Renal Medicine Chair)	Prof Simon Davies
British Association of Paediatric Nephrology (BAPN) Honorary Secretary	Dr Sally Feather
Associate Specialist Rep	Dr Yook Mun Woo
Specialist Registrar SpR Club Rep	Dr Mark Brady
Society for District General Hospitals (DGH) Rep	Dr Stephen Morgan
British Renal Society President	Dr Richard Fluck
Kidney Care Alliance Chair	Fiona Loud
Renal PatientView	Prof Neil Turner
Renal Scientists Working Party Chair	Dr Amy Jayne Mcknight
Representative for Wales	Dr Richard Moore
Representative for Northern Ireland	Dr William Nelson
Representative for Scotland	Dr Mark MacGregor
Green Nephrology	Andrew Connor

EXECUTIVE COMMITTEE (APPOINTED)

Education & Training Committee Chair	Dr Jeremy Levy
International Committee Chair	Prof Albert Ong
Research Committee Chair	Prof Fiona Karet
Clinical Services Committee Chair	Dr Graham Lipkin
Clinical Practice Guidelines Committee Chair	Dr Andrew Lewington
Equal Opportunities in Nephrology Chair	Dr Claire Sharpe
Rare Diseases Committee Chair	Dr Mark Taylor
Terminology Committee Chair	Dr Afzal Chaudhry

EXECUTIVE COMMITTEE (ELECTED)

Elected Renal Scientist	Dr Mark Dockrell
Elected Member	Dr Abraham Abraham
Elected Member	Dr Peter Choi
Elected Member	Dr Indranil Dasgupta
Elected Member	Dr Michael Robson
Elected Member	Dr Jonathan Barratt
Elected Member	Dr Sunil Bhandari
Elected Member	Dr Claire Sharpe
Elected Member	Dr Alastair Hutchison



WELCOME FROM THE PRESIDENT DR DAVID WHEELER

I have thoroughly enjoyed my first 6 months as President and would like to convey my thanks to the Trustees, the Executive and to MCI for all the support provided. I am particularly grateful to Charlie Tomson for helping my transition into the new role.

Over the last few months, we have focused on looking forward and on streamlining our operations to ensure that the Renal Association continues to provide the appropriate benefits for members, despite the budgetary constraints that have resulted from the downturn in corporate support.

The Trustees made the difficult decision to increase subscription fees (for the first time in six years), but we remain committed to ensuring that membership provides good value for money. As part of the planning process, the Trustees and MCI attended a weekend retreat back in November. Our strategic plan will help to shape the future of the organisation and is focused on five key areas including Research, Quality in Practice, Membership, Communications and Education.

Key to our future is the website, which will shortly undergo an upgrade and will incorporate a number of new features, which we believe will be useful to members. We have continued to work closely with the BRS and plan to include colleagues from the multidisciplinary team in Renal Association activities.

We have agreed a combined BRS and Renal Association meeting for 2014 and see this arrangement becoming the norm (except in 2015 when the Association is committed to a combined meeting with the ERA-EDTA). The plan for 2014 is to book a conference centre for a whole week and to encourage multidisciplinary groups to hold their own satellite meetings alongside the BRS and RA. We welcome input on how best to provide for all interested parties during "UK Kidney Week 2014". In the meantime, we hope that you enjoy our 2013 meeting with our colleagues from the British Transplantation Society in Bournemouth.

Dr David C Wheeler
President
The Renal Association



2012 REVIEW OF THE YEAR DR ALISON BROWN

It is a great honour for me to be reporting to you as the new Honorary Secretary of the Renal Association. The fact that I am in this position – a surprise to me as well as to many of you, I am sure! - is eloquent testimony to the formidable powers of persuasion of my predecessor, Lorraine Harper.

I would like to thank Lorraine not only for her work on behalf of the Renal Association over the last four years, but also for her continuing invaluable support and advice. I would also like to thank all the Renal Association Trustees, but especially the President, Dr David Wheeler, Past President Charlie Tomson, President Elect Dr Bruce Hendry, and Treasurer Dr Jonathan Fox, who have all given me much needed help and support as I try to follow in Lorraine's illustrious footsteps.

We live in exciting – if uncertain – times – and the Renal Association continues to go from strength to strength. There is a huge amount of work carried out by the Executive and Committees, and we are privileged that so many people are prepared to give up their time to contribute – especially we all struggle more and more with increasing clinical workloads. Nominations are just in to replace three Executive Members - Dr Abraham Abraham and Dr Jonathan Barratt are standing down after a three year term of office, and Dr Peter Choi is moving to Australia. Many thanks to them for their contribution to the work of the Renal Association. They are replaced on the Executive by Paul Warwicker, Consultant Nephrologist at the Lister, Stevenage, and Moin Saleem, Professor of Paediatric Nephrology from Bristol. We were delighted to have several applicants for the Executive position of consultant for less than five years, and we will know the outcome of the election for this post by the time of the AGM.

We are conscious of the need to improve communication about the work that the Renal Association undertakes on behalf of renal patients and on behalf of all our members, and we hope to improve dialogue with, and feedback from, all our membership. Our new Communications Manager, Jim Moriarty, Consultant Nephrologist from Gloucester, is working hard to improve the website and to streamline communication by tweeting important news to all our followers. I hope that the recently introduced monthly bulletin from Committee Chairs in eNews will keep everyone better informed about the current work of the committees and will inspire people to get in touch and contribute to projects in their areas of interest.

In 2012, the Renal Association awarded the AEG Raine Award to Amy Jayne McKnight for her work on unravelling heritable complexities for CKD. Walls Bursary winners were David Ferenbach and Lindsay Keir, and the Lockwood Travel Bursary was also awarded to David Ferenbach. The impressive work of the many applicants for all these awards demonstrates the continuing strength and depth of UK renal research.

Amgen continues its generous support with 10 travel bursaries awarded to attend the 2013 Joint Congress to young researchers whose work has been accepted for presentation.

Eight medical students received travel bursaries to help towards electives which include some study of nephrology – we hope their experiences will inspire them and our support will help them to become the nephrologists of the future.

The Renal Association had 1085 members during 2012, and we continue to encourage medical students, trainees and PhD students to join us by taking up our introductory one year free membership offer.

The 2012 Annual Conference in the beautiful Sage Building in Gateshead was a great success, with a total of 732 attendees and 360 abstracts submitted, with a really enjoyable programme which had something for everyone. We are tremendously grateful to the many people who contributed to the success of this meeting - the organising committee, those who submitted their work for presentation, speakers, abstract markers and session chairs, and of course everyone who attended. This Conference will be a hard act to follow but I hope that the joint Congress with the BTS in sunny Bournemouth will be just as enjoyable. For the first time we are joining together with the BTS for all three days of the conference, and the organising committee have tried very hard to coordinate the programme for a truly joint event. I am immensely grateful to everyone involved in organising the conference, especially the Programme Committee of the BTS (Chris Watson, Anthony Warrens, Richard Baker and Iain MacPhee) who have worked together with the RA Programme Committee and our Scientific Programme Committee (Amy Jayne McKnight, Mark Dockrell and Alan Salama) to organise this great event!

Under Dr David Wheeler's leadership we are thinking hard about the future direction of the Renal Association and how to ensure we remain relevant and inclusive in the years ahead. Please contact me with any suggestions you have for changes and improvements that you would like to see, and please consider putting yourself forward for positions in the Renal Association to contribute your views!

For next year, we look forward to the joint Congress with the BRS in 2014, and we hope to continue to work more closely with the BRS in the years to come.

Dr Alison Brown
Honorary Secretary
The Renal Association



ACADEMIC COMMITTEE REPORT

DR BRUCE HENDRY

The UK Kidney Research Consortium (UKKRC) met in June and December 2012. Both meetings were linked to meetings of the NIHR Renal Specialty Group chaired by Phil Kalra.

The Clinical Study Groups (CSG) that make up the UKKRC continue to pursue active programmes of renal clinical research in the UK with extensive international collaboration. After significant discussions with the HTA there has been a call for renal researchers to submit ideas for priority topics to be considered for NIHR funding. One such suggestion, the study of phosphate control in CKD, has been taken up and turned into an NIHR call for applications. We are optimistic that further areas of work suggested by the renal community will also be considered suitable to be prioritised for calls to be announced by the NIHR. This process creates an increased probability of funding for the responding applications.

In addition to this initiative, a wide range of renal projects have already received significant NIHR funding largely through the efforts of the CSG leads and teams. The number of renal projects on the NIHR portfolio and the number of patients recruited to such projects have been increasing at a significant rate (20-40% p.a.) over the past two years.

Following discussions with the British Renal Society (BRS) the RA academic team has committed to improved multidisciplinary involvement in the clinical research process. All the CSG are now seeking to harness more effectively the contributions of the multi-professional team and of patients and carers in designing and delivering clinical research.

The UKKRC has re-emphasised its multiprofessional commitment and recognises the co-leadership of the RA, the BRS and Kidney Research UK (KRUK). The role of chair of the UKKRC now rotates from me to Tim Goodship of KRUK.

The Renal Rare Disease initiative led by the Rare Disease Committee (RDC) and its chair Mark Taylor has continued to make progress. In 2012 three more Rare Disease Groups were authorised by the RDC in conjunction with KRUK bringing the total to 14. These groups are now actively designing their web-based registries and working nationally to involve patients and carers as well as the MDT in the process. We are holding a Workshop on Rare Diseases at the RSM London on July 5th 2013 where practical issues and progress will be reviewed, please consider attending.

I now present updates from the chairs of the academic committees of the RA.

Education and Training committee (ETC), Chair Jeremy Levy

The ETC continues to oversee the RA Advanced Nephrology Course run by Drs Sunil Bhandari & Paul Harden, in Oxford. This remains a highly successful five day residential course with over 90 participants (inc some from overseas); based around plenary lectures, and multiple small group workshops. We have planned three CPD sessions for the Annual Conference 2013 on viruses and renal disease, stones and their management, and medical education including an update on the Renal Specialty Certificate Examination (SCE). The Exam continues to be extremely successful managed by Dr Jonathan Fox, with Dr Neal Padmanabhan replacing Jeremy Levy as secretary to the exam board, supported by over 40 UK consultants writing, reviewing, standard setting and validating the questions. Pass rates remain very high for UK trainees.

We have had extensive discussions about renal web training activities and whether the RA should develop its own, but have elected not to do so. We are aiming to signpost high quality on-line materials from other providers, and better use the RAs enhanced web presence. Similarly we aim better to enhance the use of patient decision aids in training in renal medicine such as those

developed by the National Clinical Director for Kidney Services. We are currently undertaking a study of the core minimal renal undergraduate curriculum and establishing current practice across the UK medical schools. Finally we have been involved in ongoing discussions about the size of the medical training workforce through the renal SAC and other bodies, and with the RCP in enhancing the training of health care scientists linked with renal medicine.

International Committee (IC), Chair Albert Ong

A Joint meeting co-sponsored with ISN is planned at the RA-BTS meeting and this will be titled Global Nephrology. A second RA-ISN fellow has been appointed and we congratulate Dr Ahmad Nassary (Afghanistan) who will work at the Hammersmith Hospital hosted by Edwina Brown. The IC membership is changing with proposed new members Indy Dasgupta (Exec) and Kjell Tullus (BAPN) replacing Peter Mathieson and Mignon McCulloch.

Research Committee, Chair Fiona Karet

The Research Committee has expanded during the past year to include better representation from the Rare Diseases Community, the non-clinical scientists grouping, and those with trials and epidemiology experience. It has continued to work mostly via email and conference call. It has received reports of the UKKRC meetings but has otherwise had a quiet few months, as we are still waiting for the programming side of the research database to be completed. Committee members have contributed to the development of the Bournemouth scientific programme, and non-clinical researcher opportunities to present are plentiful. Academic Trainee and Renal Scientist careers sessions are planned on the Friday.

Dr Bruce Hendry
Vice President
The Renal Association

CLINICAL COMMITTEE REPORTS

DR MARTIN RAFTERY

The Clinical Affairs Board (CAB) meets three times per year, usually at a venue in London. It is chaired by the Clinical Vice President and is attended by the Chair of the UK Renal Registry, the Chair of the Clinical Practice Guidelines Committee and the Chair of the Clinical Services Committee. It is also attended by two nominated members of the Executive Committee and is normally attended ex officio by the National Clinical Director for Renal Services and occasionally by the President of the Renal Association. It tries to integrate the planning and work of the above organisations and represents the Renal Association (RA) on the development of national policy, the planning of renal services and is one of the instruments by which the RA responds to National and Regional consultation documents of relevance to the renal community and to the care of renal patients. It is also a registered stakeholder with NICE and regularly nominates RA members to serve on Appraisal Committees.

The Chair of the Clinical Practice Guidelines Committee is Dr Andy Lewington and he has recruited many new Renal Association members to update guidelines as they fall due for revision. A decision has also been reached to recruit other members of the Multi-Disciplinary Team to assist in Guideline development where appropriate. Thus the new guideline on Water Treatment quality has been written in conjunction with the Association of Renal Technicians and has been ratified in early 2012. A new guideline on the treatment of Hyperkalaemia has been added in 2012 and four of the existing guidelines were reviewed in 2012 and a further five are due in 2013.

All of the final versions are available on the main guidelines page of RA website at:

<http://www.renal.org/Clinical/GuidelinesSection/Guidelines.aspx>

The committee continues to work closely with KDIGO in providing feedback on the KDIGO Nephrology Guidelines which are applicable worldwide. The Committee is currently working on collaborative guidelines with other specialist societies and one on contrast induced AKI jointly with the British Society of Interventional Radiologists and the British Cardiovascular Intervention Society was ratified in 2012. Details of these guidelines are available on the future guidelines page of the RA website at:

<http://www.renal.org/Clinical/GuidelinesSection/FutureGuidelines.aspx>

The CAB signed off all of the final versions of the guidelines.

Work on Payment by Results (PbR) was completed in 2010 and all the versions were shared with CAB. The plan was for a mandatory best practice for dialysis from 2011-12. The target for best practice for haemodialysis had a target of 75% arterio-venous fistulas in 2011-12 and this has risen to 80% in 2012-13. Following discussions in CAB with the national Clinical director for Kidney Care it has been decided to maintain the target at 80% for 2013-14. It has also been decided to retain the exclusions applicable in 2012-13.

There remains a challenge for many renal units as the £20 billion savings required by the Department of Health has resulted in challenging cost improvement programmes put in place by many financial directors of NHS acute Trusts. This combined with a real terms reduction in PbR tariff for the past 2 years has put Renal Units in England under significant financial pressure. The CAB has been working with the National Clinical Director for Renal Services to ensure that those financial pressures do not result in a decline in quality or a reduction in access to renal services provided.

The CAB on behalf of the RA made a submission to the Future Forum chaired by Professor Steven Field and commissioned by the Secretary of State for Health in 2011. It was emphasised that renal patients perhaps

more than most required integrated care throughout their lives on renal replacement therapy and the risk of fragmentation of services implicit in the proposals could profoundly disrupt the integration. The changes caused by these proposals and the Health and Social Care Act are about to go live in April 2013 and many of the structures are already being put in place including separate Clinical reference Groups for Dialysis and Transplantation. CAB was delighted that a substantial proportion of Renal Replacement Services will be centrally commissioned and as such the risk of fragmentation is reduced. There are some gaps however which risk variation in access and in quality between Clinical Commissioning Groups.

CAB has been heavily involved working with the Kidney Alliance and the National Clinical Director on the proposed tariffs for dialysis away from base (DAFB) and for Home Haemodialysis. The compromise tariffs that have been proposed are an improvement on the original proposals and it is to be hoped that they will result in continued access of our patients to these modalities of treatment.

The Joint Specialty Committee for Renal Medicine is a collaboration between the RA and the Royal College of Physicians of London (RCP). It is chaired by the immediate past President of the RA and is attended by several RA members representing many aspects of planning renal services, ensuring high quality service delivery and the training of staff. This allows the RA to use the influence of the (RCP) in achieving our quality and access to service targets for our patients.

Dr Martin Raftery
Clinical Vice-President
The Renal Association



UK RENAL REGISTRY REPORT DR DAMIAN FOGARTY

On behalf of the staff in the registry it gives me great pride and satisfaction to report that 2012 was our busiest year for some time. Ron Cullen as Director and all the staff have worked tirelessly to help improve our role in monitoring patient care for those with CKD. We continue to build on our established role as the national source of NHS healthcare data on patients dependent on renal replacement therapy across the four nations. As well as progressing with the core annual report work on activity and outcomes for RRT patients we have extended our work to include pilot studies in CKD, AKI and support for the Rare Renal Disease Initiative and a number of major studies such as the ATTOM project. For our core work our focus for the last 18 months has been on improving the speed and processing of data. This now means that in 2013 we will publish the equivalent of two reports covering new and prevalent patients at the end of 2011 and the end of 2012. The 2012 report on activity until the end of 2011 will be published in June.

Despite the widespread recognition that incident rates of established renal failure (ESF) have plateaued our work using your units' data shows that the prevalent numbers increase by 4% per annum as patients live longer. There is recognition in this that the age and comorbidity of these patients also increases and places demands on units. Of course this is only one aspect, albeit the largest, of nephrology care and the following outlines our progress with the wider areas that we would like to help more with.

Extending National Audit to Other Areas of Nephrology

We have been partners with colleagues in the Royal College of General Practitioners and the NHS Information Centre in planning the first national **audit of CKD using primary care data**. You will no doubt

hear more on this but it is important that our renal units promote this locally as one way to prevent progressive CKD is earlier recognition and education of colleagues in a range of disciplines. Another area of substantial growth and thus need for input from the registry is Acute Kidney Injury (AKI). Recent US data (Hsu C et al J Am Soc Nephrol. 2013 Jan doi:10.1681/ASN.2012080800) has shown that the rate of dialysis requiring AKI has doubled in the past decade to 533pmp in 2009 a rate much higher than the RRT rates. We are thus helping the commissioners in England with regard to a national audit of **AKI requiring dialysis in renal units**. This is to be included in the CQUIN (Commissioning for Quality and Innovation) payment for each trust beginning in 2013/14. We have not been closely involved in the precise design of the indicator but want to position ourselves to learn from these first cycles and help measure and thus help units reduce the rates of severe AKI. Finally we would like to capture data on patients with **conservatively managed ESF** but this is proving a thorny issue as the role and responsibility is shared across the primary and secondary care sectors.

Paediatric Nephrology

We have continued to work closely with the 13 UK paediatric renal units to help improve the way that data on RRT patients is transmitted to the registry. In this we have been lucky in securing the first **Tony Wing award** to allow a paediatric fellow to work with us in the registry on improving this aspect of our work. This is a British Kidney Patient Association award in memory of Dr Wing (1933-2012) who was pivotal in setting up and supporting renal registries in the 1970s and 80s. As chairman of the EDTA registry (1977-1983) he was very aware of how the UK was providing a reduced level of RRT services to its patients, a reminder of the power of basic data to change the service for our patients. It is thus entirely apt that his name should be associated with a project that will help children on RRT achieve better outcomes in this current era.

Francis Enquiry - Implications for the Registry

Unless you have been on another planet you cannot have missed this important and shocking report. There is no doubt that this will help shape hospital services and wider NHS care for the next 20+ years. The importance of assessing care of patients through local and national audit and outcome systems is perhaps a minor aspect in this report and rightly the personal suffering and absence of care takes prominence. However it does make us reflect on *what we do to maximise care* for RRT patients. The registry forms a critical aspect of this and for a number of years we have published de-anonymised centre specific reports on survival of RRT patients. These now take on a greater prominence and will we hope be scrutinised more than before. Last year we sent letters to six units with lower than expected survival at one year for patients on RRT (most usually for those patients on centre based haemodialysis). We are still in some final discussions with those units regarding the meaning and communication of these results (internally at trust level) but as we look to the new unpublished 2011 data we do see improvement with all those units moving back towards the mean for survival across the country. So what elements of the Francis enquiry are relevant to us: Firstly there is a need for all "to accept common information practices, and to feed performance information into shared databases for monitoring purposes." We have been doing this for some time but quoting again from the report "Systems should, where practicable and proportionate, be capable of collecting performance management and audit information automatically, to avoid unnecessary duplication of input." Trusts have paid varying levels of attention to these operational aspects (for instance data for Vascular Access Audits) so now we have to ensure we use the opportunities to help our units and patients. Furthermore our reports have until recently not included patient experience data. We will work towards redressing this and indeed some recent work on shared decision making and a pilot Patient

Reported Outcomes study will be a start for us in addressing and measuring how our care in renal units meets the expectations for our patients.

Thankfully in many quarters what we are doing is highly regarded (See Tavare BMJ 2012;345 doi: <http://dx.doi.org/10.1136/bmj.e4464>) but many of us within the UKRR recognise we can always do things better, more efficiently and in a more timely and relevant way for the patients and their units.

The UK Renal Data Collaboration

The UK Renal Data Collaboration was launched at a meeting in Edinburgh on 29 Nov 2012 when the Chairs of the UKRR, SRR, BAPN, RaDaR and RPV met and agreed to work together and with the renal IT suppliers and the NHS to improve the way we handle data.

Renal medicine in the UK leads the field in electronic patient records. All UK renal units use them, most have extensive links to lab and patient admin systems and some are almost paperless. Organised storage and reuse of data by units improves care

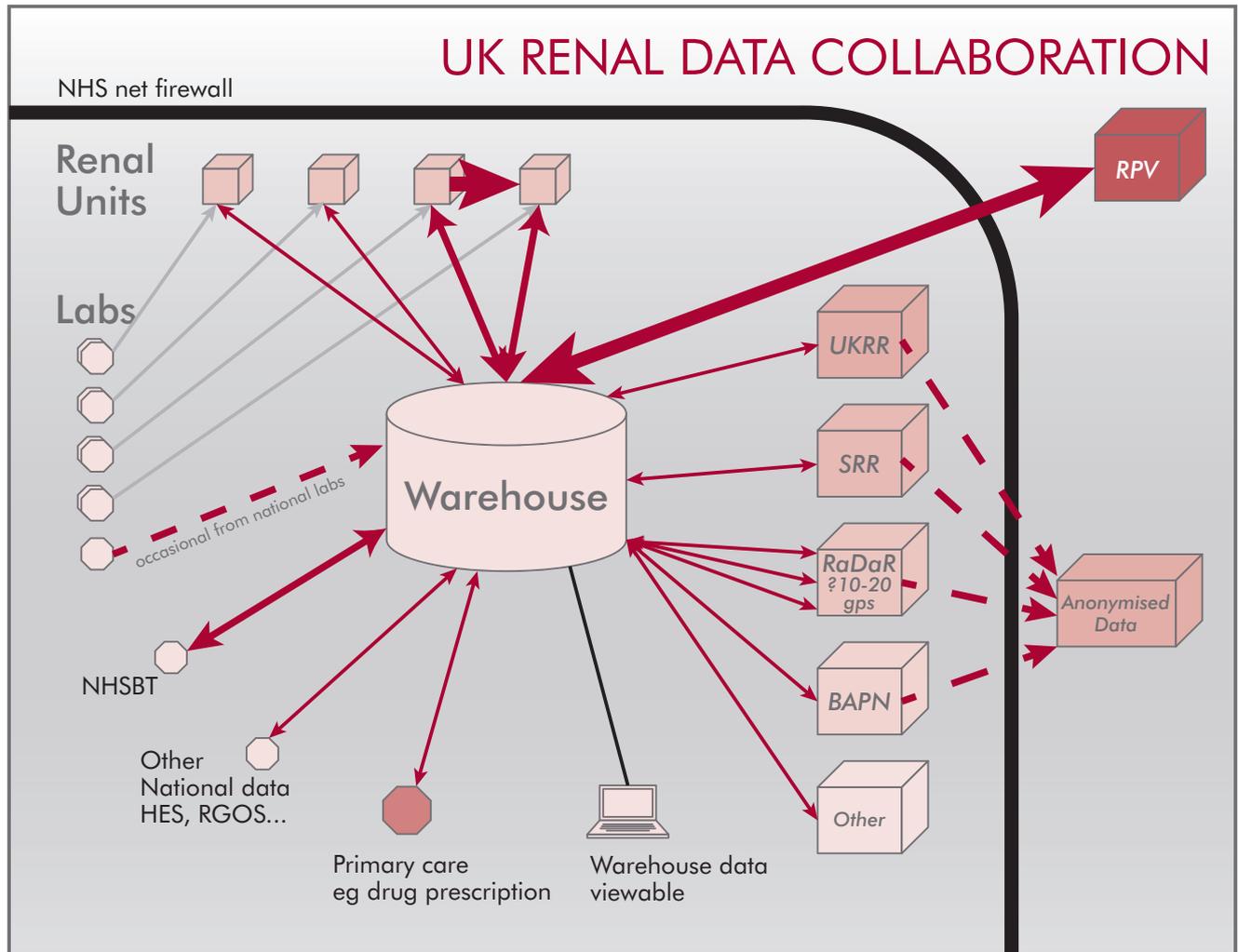
and enables patients to have access to their records. It also allows registries and research groups to support quality improvement, research, service development and teaching. This all started without much planning in the 1970s and hundreds of different electronic file formats and message structures have emerged. It works, but is often slow (months to validate registry data), inflexible (can't add new data fields), high maintenance (skilled local knowledge required), can't be reused and precludes modern analytic techniques which could reveal unsuspected things.

The proposal is to set up a data warehouse which will sit at the hub of our data communications between renal units and the UKRDC 'clients'. Adoption of standards for data transmission will improve speed, reliability and reusability. The UKRDC is supported by the UK Terminology Centre which helps with rapid registration of new SNOMED CT diagnostic terms, data labels (eg pre H dialysis PTH using a named assay) and access to other experts. An outline diagram of what we envision broadly is below. We are keen to canvas further opinions and views on this.

Medical Director

As we expand our areas of work it is apparent that the regular input from a senior clinician is vital. The UKRR Chairman's role has therefore been changed to a half-time equivalent Medical Director role. This role will not also encompass an RA Trustee duty thus releasing time and other responsibilities and thus creating the right structures for the UKRR and indeed the Renal Association. Please watch the e-news in April and May for the expression of interest and feel free to discuss with me the role.

Dr Damian Fogarty
Chair
UK Renal Registry





BAPN REPORT DR JANE TIZARD

It was a great privilege to have been elected to the role of President of the British Association for Paediatric Nephrology (BAPN) in 2012. Firstly, I would like to thank Mary McGraw who provided such excellent leadership of the BAPN over the past three years and I will endeavour to keep up her very high standards. It has been a busy few months but I am thoroughly enjoying the challenge so far. As BAPN President I am a Trustee of the Renal Association and a member of the RA Executive Committee and The Renal Registry Management Board.

Within the first few months of this role I have felt tremendous support from the other Trustees and members of these committees as they listen to and consider the needs of children with renal disease at every opportunity and I am very grateful for this.

The BAPN executive meets quarterly and reports to the BAPN at the RA Annual Conference and at our winter meeting which combines a business meeting with clinical, academic and clinical services updates. We aim to raise the quality of care for children with renal disease through the work of the BAPN in a variety of areas.

The paediatric renal registry has continued to develop successfully. Last year Carol Inward completed her term as Chair of Paediatric Registry and Audit Committee and this position was taken up by Manish Sinha. The ability of units to submit electronic data has been the biggest challenge over recent years and this is now possible in almost all units. Two important projects that have recently been presented relate to the demography of renal replacement therapy (RRT) for young adults (16-25 years) in the UK and late presentation of children in established renal failure.

Audits are being undertaken of anaemia in children on renal replacement therapy and a more detailed audit of children under the age of two on RRT (both funded by the British Kidney Patient Association (BKPA) and renal biopsy in children).

We are delighted that the BKPA and Kidney Research UK have collaborated to establish a new post at the UK Renal Registry, in memory of Dr Tony Wing. This post will focus on the collection of data from both children and young adult patients - a group of patients recognised as particularly vulnerable in the kidney care system. The Rare Diseases Registry continues to expand under the leadership of Mark Taylor who chairs The Rare Diseases Committee. Eleven new groups have been approved that can recruit from paediatric sites.

Research has continued to thrive over the past year initially under the leadership of Moin Saleem who chaired the Medicines for Children Research Network Paediatric Nephrology Clinical Studies Group until mid-2012 when Richard Coward took over this position. This group has markedly improved the co-ordination of BAPN research. There are now two NIHR funded studies led by Nick Webb: PREDNOS which is comparing standard versus long tapering of steroids in minimal change nephrotic syndrome which is progressing well and PREDNOS II which is assessing the role of daily steroids for nephrotic syndrome patients with intercurrent infections which will commence in 2013. Another active study is HOT KIDS - The Hypertension Optimal Treatment in Children with Chronic Kidney Disease study led by Manish Sinha. Richard Coward and Sally Hulton now share the post of BAPN Research Secretary and regularly support trainees in their academic development.

The guideline group chaired by David Milford have continued work on new guidelines and updating current guidance and this year hope to work more closely with the adult guideline development. The infoKid project developing a new online information resource for parents and carers about children's kidney conditions is a partnership project of the RCPCH, the BAPN and the BKPA is due to be launched this autumn.

One of the current challenges for us is the new commissioning arrangements for specialised services. Over the past year I have represented Paediatric Nephrology on the Paediatric Medicine Clinical Reference Group developing an agreed service scope and specification. It is an opportunity to define the best model of service to try and deliver the optimal care to our patients. We hope to build on the work on Paediatric Nephrology networks that Mary McGraw undertook and to develop more comprehensive commissioning of the whole patient pathway. Dal Hothi our clinical services lead has started work with the BAPN membership in some of these areas.

There are many others who have contributed to the work of the BAPN and I would like to thank all those who have represented the Association over the past year and the members of the BAPN executive committee for their support over my first few months in office but particularly Sally Feather who as Honorary Secretary of the BAPN continues to ensure that the BAPN runs efficiently and whose knowledge of the BAPN has been invaluable.

Dr Jane Tizard
President
British Association of Paediatric Nephrology



TREASURER REPORT

DR JONATHAN FOX

At the end of 2012, the Renal Association's overall deficit for the year was £3,962, which represented a major improvement from the deficit of £83,436 in 2011.

This was despite the loss of a further two corporate members (from seven to five) and a deficit of £16,087 from the Annual Conference. Individual membership was stable at 1085 and subscriptions, individual and corporate, remained the major source of income; our secretariat (MCI) has worked hard to improve the collection of individual membership fees and this has resulted in a significantly higher subscription income. The highly successful Advanced Nephrology Course also made a significant contribution (£27k).

The Renal Registry Fund had a surplus of £25,948 at the end of 2012; capitation fees provide most of its income.

The pie charts on the following pages give an overview of income and expenditure for the Renal Association and for the UK Renal Registry in 2012, broken down into their component parts. For further details, please see the full financial statement for 2012 which is available at www.renal.org

The Renal Association Fund holds within it separate funds for the British Association of Paediatric Nephrology and for the Nephrology SpR Club. The UK Renal Registry manages the finances of Renal

Patient View which is funded by capitation fees (Scotland excepted).

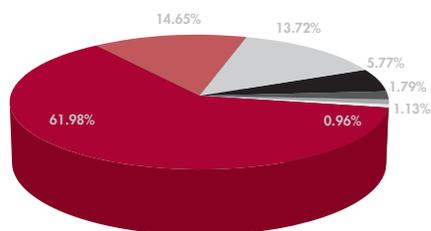
The reserves of the Renal Association and of the UK Renal Registry remain adequate. Compared with the end of 2011, the Renal Association Fund had decreased slightly from £374,018 to £370,059, and the Renal Registry Fund had increased slightly from £1,290,634 to £1,316,581. Total reserves still equate to approximately 11 months of expenditure across the Renal Association and UK Renal Registry.

Further progress has been made in reducing the number of debtors (both corporate and individual), and there are now no significant old debts.

Overall, the finances of the Renal Association and of the UK Renal Registry remain secure. For 2013, the priorities are to make every effort to ensure that the Annual Conference does not produce a significant deficit and to increase the number of corporate members.

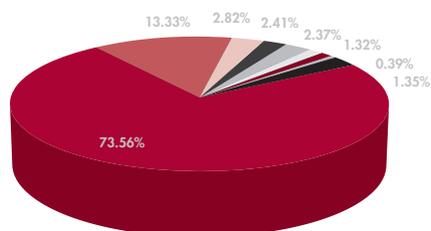
Dr Jonathan Fox
Honorary Treasurer
The Renal Association

TREASURER REPORT



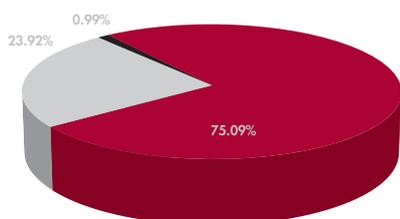
RENAL ASSOCIATION INCOME 2012 - £520,287.47

Meeting Income Registration fees 61.98% Bursary Income 0.96%
 Corporate Subscriptions 5.77% Bank Interest Received 1.79%
 Membership Subscriptions 14.65% Sponsorship Income 1.13%
 Other Income 13.72% Advertising Income



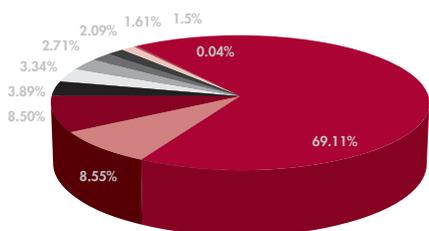
RENAL ASSOCIATION EXPENDITURE 2012 - £524,249

Meetings 73.56% Donations Made 1.32%
 Trustee and Committee Expenses 2.41% Electronic Communications 2.82%
 Awards and Bursaries 2.37% Other Expenses 2.44%
 Secretariat Fees 13.33% Bank Charges & Interest 1.35%
 Coalition Membership Fees 0.39%



UK RENAL REGISTRY INCOME 2012 - £1,341,752

Donations Received Grants 23.92%
 Consultancy Income Capitation Fee 75.09%
 Other Income Project Fees 0.99%



UK RENAL REGISTRY EXPENDITURE 2012 - £1,325,189

Staff Salary Costs 69.11% Postage/Sundries 1.61%
 Legal and professional Fees 8.55% Office Overheads 2.71%
 Staff Expenses 3.89% Meeting Room Costs 2.09%
 IT Costs 8.50% Depreciation 1.5%
 Staff Training and Development 3.34% Bad Debts Written Off 0.04%

THE RENAL ASSOCIATION

founded 1950



TRUSTEES

EXECUTIVE
COMMITTEE

CLINICAL
AFFAIRS BOARD

ACADEMIC
AFFAIRS
BOARD

TERMINOLOGY
COMMITTEE

CLINICAL
SERVICES
COMMITTEE

REGISTRY
COMMITTEE

RESEARCH
COMMITTEE

INTERNATIONAL
COMMITTEE

CLINICAL
PRACTICE
GUIDELINES
COMMITTEE

EQUAL
OPPORTUNITIES
IN NEPHROLOGY
COMMITTEE

RENAL
PATIENTVIEW
COMMITTEE

EDUCATION
& TRAINING
COMMITTEE

RARE
DISEASE
COMMITTEE

AWARDS AND BURSARY WINNERS

Renal Association awards and bursaries are annually available to all members.

AEG RAINE AWARD

The Raine Award was established in memory of Tony Raine, Professor of Renal Medicine at St Barts, following his tragically early death in 1995.

This prestigious annual award is made to a relatively junior investigator (usually 35 years of age or less) who has made a significant contribution to renal research, especially through presentations made at the Renal Association Annual Meeting.

In 2012 the AEG Raine Award was awarded to Amy Jayne McKnight.

WALLS BURSARIES

These bursaries were established in memory of the late Professor John Walls, President of the Renal Association 1995-1998, who died in 2001. Their aim is to help Renal Association members to spend short periods (e.g. weeks or months) at other centres, generally outside the UK, to learn new laboratory techniques or gain new clinical skills

In 2012 the Walls Bursaries were awarded to David Ferenbach and Lindsay Kier.

LOCKWOOD AWARD

These were established in memory of the late Dr Martin Lockwood, a distinguished investigator and active member of the Renal Association, who died in 1999. They are the successor to the Milne-Muehrcke award. Its aim is to help Association members present work at the American Society of Nephrology and combine this with a visit to a collaborating laboratory or clinical nephrology unit in the USA.

In 2012 the Lockwood Award was presented to David Ferenbach.

MEDICAL STUDENT ELECTIVE BURSARIES

The Renal Association awards bursaries each year to medical students undertaking electives which include a significant renal component, either clinical or research.

In 2012 Bursaries were awarded to Wajihah Arshad, Sharmili Balarajah, Rebecca Cox, Peter Murray, Lisa Li, Emma Bradbury, Anthony De Souza and Anchala Raveendran.

AMGEN BURSARIES

In 2012, 10 Amgen Bursaries were awarded to the higher scoring Renal Association member abstract applicants.

The recipients were:

Zoe Golder
Miriam Berry
James Fotheringham
Simon Freeley
Lynsey Webb
Zanzhe Yu
Elizabeth Swan
Edwin Wong
Eve Miller-Hodges
Rishi Pruthi

2012 NEW MEMBERS

Mr Nima Abbasian
Dr Fatima Abdelaal
Miss Emma Aitken
Dr Naseeb Akhtar
Asmaa Y Mohammed Al-Chidadi
Dr Omer Ali
Dr Muhiad Ali
Dr Abdel Galil Ali
Ms Emma Amir-Ebrahimi
Dr Mona Aslam
Dr Phillippa Bailey
Ms Sián Baker
Dr Sheetal Bhojani
Dr Chris Carrington
Dr Sheung Chan
Mr Mohamed Chunara
Dr Candice Clarke
Dr Andrew Connor
Dr Georgina Cope
Miss Alice Coughlan
Miss Holly Courtneidge
Dr Zoe Cousland
Dr Emma D'Amato
Dr Catherine Derry
Miss Megan Devlin
Dr Lynn Diskin
Mr Maurice Dungey
Dr Sarah Edwards
Dr Rhys Evans
Dr Thomas Forbes
Mr Simon Freeley
Dr Paul Gamble
Dr Christine Gast

Miss Zoe Golder
Dr Eleanor Hay
Dr Manvir Hayer
Dr Wesley Hayes
Dr Muhammad Imtiaz
Dr Mark Jesky
Dr Surabhi Jindal
Dr Thomas Jorna
Dr Michael Kelly
Mrs Sahithi Kuravi
Dr Raman Lakshman
Dr Gareth Lewis
Mr Tarunkumar Madne
Dr Frances Marr
Mr Carl May
Dr Istuan Mazak
Dr Johanna Maziar
Dr James McCaffrey
Dr Gerry McKay
Dr Nicholas Medjeral-Thomas
Mr Bvasudev Menon
Dr Madhu Menon
Dr Simon Meyrick
Dr Sotirios Mikros
Dr Emma Montgomery
Dr Balan Natarajan
Dr Chaudhary Mohammed Junaid Nazar
Dr Amanda Newnham
Dr David Oskiera
Dr Sabina Pahari
Miss Katherine Parker
Dr Jean Patrick
Mr Hugo Penny

Prof Jacob Plange-Rhule
Dr Ashok Poduval
Dr Hitesh Prajapati
Dr Thomasz Rajkowski
Dr Raina Ramnath
Dr David Randall
Dr Anirudh Rao
Dr Carmen Rasann
Dr Simon Rhodes
Dr Victoria Robins
Dr Ruben Roy
Dr Hannah Sammur
Dr Praveen Sana
Dr Nadia Sarween
Dr Rabya Sayed
Dr Nileshkumar Shah
Mr Ruchir Singh
Dr Jamie Smith
Dr Edward Smith
Dr Jelena Stojanovic
Miss Elizabeth Swan
Dr Dominic Taylor
Dr Anita Thangavelu
Dr Kah Mean Thong
Dr Shiva Prasad Ugni
Dr Chris Upton
Mr Owen Vennard
Dr Elisabetta Verderio Edwards
Ms Gráinne Walsh
Dr Kathryn Watson
Dr Eranga Wijewickrama
Dr Emma Wylie
Mrs Hannah Young

2012 CORPORATE MEMBERS

AMGEN

Baxter

janssen 

 **NOVARTIS**

 **Shire**

DATES FOR YOUR DIARIES

RA-RSM RARE DISEASE WORKSHOP

RSM London

Friday 5 July 2013

ADVANCED NEPHROLOGY COURSE

Corpus Christi, Oxford

Monday 6 to Friday 10 January 2014

UK RENAL WEEK

Hosted by The British Renal Society and The Renal Association

SECC, Glasgow

Tuesday 29 April to Friday 2 May 2014



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Fax: 01730 715 291
Email: renal@mci-group.com



www.renal.org