

Caring about people with kidney disease

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Cross Party Group on Kidney Disease **AGM Minutes**

5pm, Tuesday 14th December 2004
Scottish Parliament
Room Q1-03
Edinburgh

MINUTES

Present

Margaret Jamieson MSP
Dr Jean Turner MSP
Mary Scanlon MSP
Kenny MacAskill MSP
Jamie Stone MSP

Jane Bryce
Professor Sandy Davison
Berkeley Greenwood
Dr Andrew Innes
Dr Brian Junor
Charles Kernahan
Dr Graham Knox
Peter MacDonald
Jen Lumsdaine
Nick Turkentine
Michael Nation
Professor Andrew Rees
Katie Ronald
Dr Keith Simpson

Apologies

Janis Hughes MSP
Eleanor Scott MSP
Brian Adam MSP
Richard Baker MSP
Dr Chris Isles
Mr John Forsythe

1. Nominations

Margaret Jamieson MSP was re-elected Convenor of the Cross Party Group on Kidney Disease. Mary Scanlon MSP and Professor Andrew Rees were elected Vice-Convenors. The National Kidney Research Fund will continue to act as Secretariat.

2. Update from Chair of Specialist Advisory Group to the Cross Party Group on Kidney Disease – Professor Andy Rees

Professor Andy Rees gave an update on the work of the Cross Party Group and the Specialist Advisory Group of the CPG. This included;

- **April 2004 - The successful launch of two reports by the Cross Party Group on Kidney Disease.** The first entitled “Renal Disease in Scotland – A Strategy for Future Management” outlined a series of 38 recommendations designed to deliver improved management of renal disease over the next ten years - from early detection through to end-stage kidney failure and transplantation. It also detailed the extent of the renal challenge to the NHS in coming years and looked closely at the need for a multi-disciplinary team and adequate staffing levels, to treat patients with chronic kidney disease.

“Renal Disease in Scotland – Consulting with Patients” was a supplementary report published by the Cross Party Group (CPG). It described in detail the two main consultations commissioned by the CPG, including the largest ever survey of over 2,000 dialysis patients from all renal units in Scotland. Also detailed were the results of a day-long focus group event involving 34 dialysis and transplant patients and carers, from across the country. Both exercises gave the CPG an invaluable detailed impression of patients’ experience, and aimed to allow patients the opportunity to shape the recommendations put forward by the CPG and to have input into creating a patient-centred vision for renal services for the next ten years.

- **24th November 2004 - Meeting with the Minister for Health, Andy Kerr MSP** and other Scottish Executive’s Health Department officials including Mr Will Scott and Mr Michael Cornbleet. Professor Andy Rees outlined the main points raised at this meeting with the Minister. They were;
 - o The need for, and value of, the CPG reports. The existing NHSQIS document was acknowledged as a good foundation that focussed primarily on patients already with end-stage renal failure and set standards for treatment of that patient body. It was pointed out that it did not take a strategic look at how renal services will need to develop over the next ten years and that the CPG reports aimed to do this. The CPG reports wanted to make patient-centred recommendations designed to provide a patient-centred service able to cope with a doubling of dialysis patients over the next ten years, as well as better identification and treatment of those with chronic kidney disease.
 - o The need for a National Plan and National Managed Clinical Network - with treatment being delivered and organised locally but according to a National Plan. Alongside this the CPG recommended the need for a National Quality Assurance Scheme – the basis of which is already provided by the Scottish Renal Registry.
 - o The looming issue of chronic kidney disease and the need to integrate kidney care into current high priority areas like cardiovascular disease,

coronary heart disease and hypertension as well as chronic disease management plans and other disease areas like the Diabetes Framework. The Scottish Executive officials were also informed of new statistics that suggests 5-10% of the population may have some sort of chronic kidney disease, making it more common than diabetes. It was emphasised that a proportion of these people will go on to develop progressive kidney failure and have increased co-morbidity ie cardio vascular disease etc.

The main outcomes from the meeting with the Minister for Health were then outlined.

They included;

- The Scottish Executive Health Department looking again at why the decision not to create a Managed Clinical Network had been taken. It was also suggested by officials that it may be a good idea to consider a regional network as being more manageable
- Acknowledging the need to better identify and treat patients with Chronic Kidney Disease
- Creating opportunities for the CPG to have input into the Diabetes Framework Review, Chronic Disease Management plans, and the Coronary Heart Disease consultation
- The Minister agreeing to meet members of the CPG again

Professor Andy Rees concluded that the meeting with the Minister had been constructive and that it was good to open dialogue with the Minister and the Health Department.

- Dr Jean Turner MSP re-iterated the urgency of the situation and the need for improvement not only for dialysis and transplantation but also to the earlier identification and treatment of chronic kidney disease. It was also suggested that better blood testing and improved liaison between different specialists such as diabetes, kidney disease and obesity could all greatly assist the management of chronic kidney disease.
- Dr Keith Simpson supported Dr Jean Turner's comments and made reference to the possible addition to SCI Store of a calculated value for presenting kidney function. This could be displayed along with the serum creatinine result and some on-line advice about further investigation, management and referral to a Nephrologist. He felt that this would lead to better and earlier identification of kidney disease.
- It was agreed that there was a real need for an integrated programme that measures the CVD risks and outlines clear protocols, timelines and guidelines to identify kidney problems in the primary care setting.
- **Professor Andy Rees then informed the CPG of the development of a new SIGN Guideline on Chronic Kidney Disease**, as recommended within the CPG's April Report. The inaugural meeting of the SIGN Guideline Development Group is scheduled to take place on 26th January 2005 and the group aims to have a Guideline within two years.

- **Professor Andy Rees then informed the CPG that the Specialist Advisory Group had met on 6th December** to discuss the meeting with the Minister and pull an action plan together. The group agreed they were still committed to pushing for a National Plan and Managed Clinical Network. In general, the action plan will use the CPG reports as leverage to introduce change within renal services in Scotland. The group identified the following specific actions;
 - Continuing dialogue with the Minister for Health and the Scottish Executive Health Department and extending an invitation to visit the Scottish Renal Registry to illustrate the systems already in place that could support the easy transition to a National Managed Clinical Network. During the visit it was also proposed that a demonstration of the Patient View project could be given, Chronic Kidney Disease stats could be profiled and any cost benefit analysis that were available could be presented
 - To make contact with Professor David Kerr about the review of NHS Services
 - To contact all NHS Boards requesting a response to the reports and highlighting some key challenges – ie Chronic Kidney Disease.
 - The preparation of constituency-specific, renal profiling of patients and services (to include Chronic Kidney Disease stats where possible). These constituency profiles would then be presented to constituency & regional MSPs as part of a request to them for their support of CPG recommendations, particularly the need for a National Plan, etc

- **Those attending the AGM also agreed that other areas of action the CPG may wish to consider were;**
 - Tabling of relevant parliamentary questions
 - Member's Debate on Kidney Disease
 - Dialogue with those responsible for developing the Community Health Partnerships
 - The wider implications of the Patient View project currently being piloted in Scotland, giving patients and their healthcare providers direct access to blood test results, disease and treatment information over the internet, and the desired improvements that could be brought about as a result.

Margaret Jamieson MSP then closed the meeting.