

European Kidney Health Alliance



Why EKHA?

Kidney disease presents a serious challenge for the people of Europe and those responsible for providing their health care

but policy makers don't know!



EKHA – unique alliance

A single voice representing the
combined views of the renal
community

European Kidney Health Alliance (EKHA)

CEAPIR



ERA-EDTA



EDTNA/ERCA

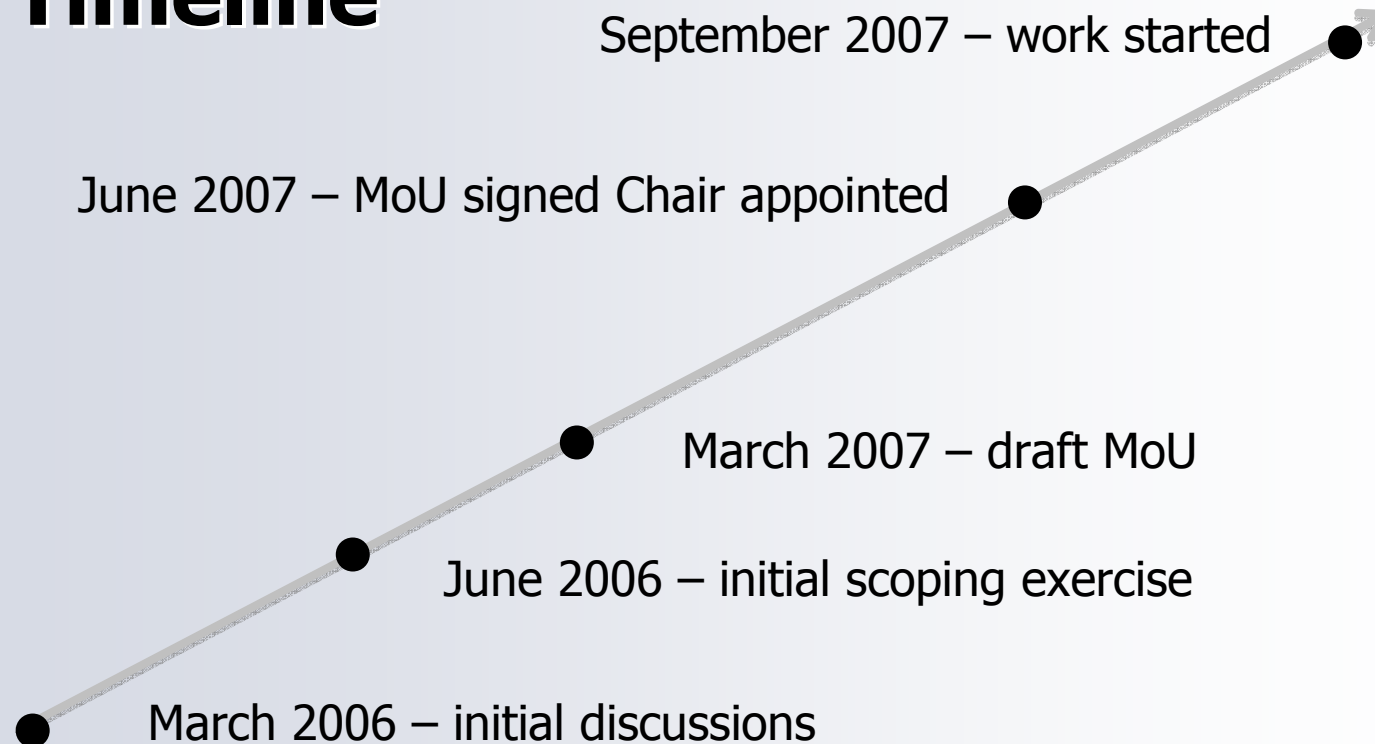


ISN



The development of the EKHA

■ Timeline



EKHA – fundamental objectives

- **Raising awareness**

- Threat posed by CKD
- Inequities of care for CKD

- **Promoting**

- Uniform standards of care
- Research and development
- Co-operation with the EU organisations
- Exchange of information

EKHA – working methods

- **Management Committee**

- Independent Chair (Andy Rees)
- Two representatives of each organisation
- Determine goals and strategy

- **Professional Lobbying Company**

- Logos
- Supply expertise, advice and Secretariat

EKHA – the philosophy

- Improve the lives of those with kidney disease or at risk of developing kidney disease
- Utilise the instruments of the European Union to achieve this objective

The European Union

- Comprised of 27 independent states with a combined population of 400 million people
- Contains states of very different sizes and cultures
- Multiple different healthcare systems

EU competencies

- Divided into three 'pillars'



Pillar 1: European Community policies

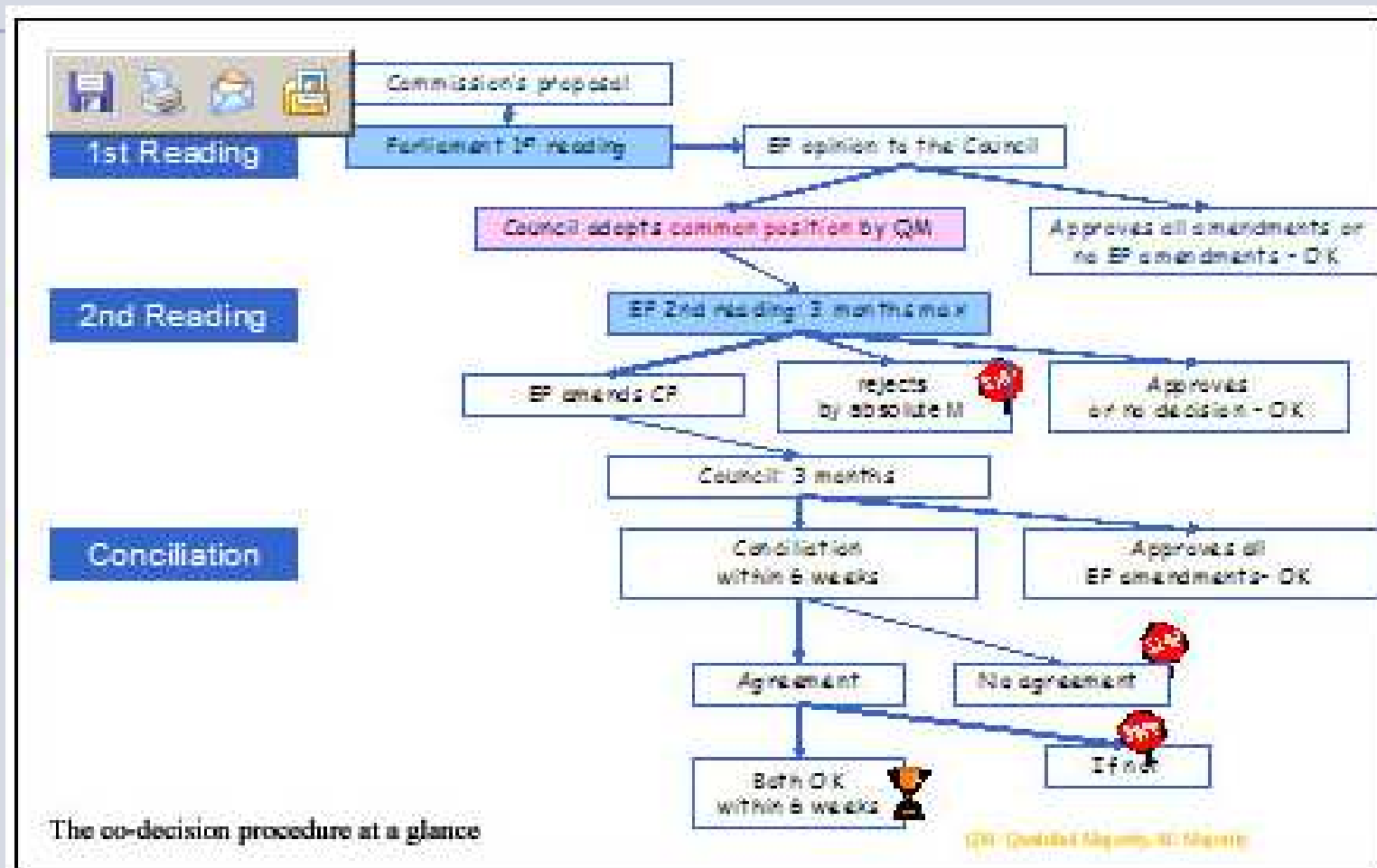
- Common policies
- Customs union and internal market
- Economic and monetary policy
- Industrial policy
- Regional policy
- Economic and social cohesion
- Employment and social policy
- Energy
- Research and development
- Environment
- Consumer Protection
- Culture
- Audiovisual Policy
- **Public Health**
- Education
- Trans-European networks
- Development aid
- Competition
- Taxation and approximation of EU laws
- Judicial cooperation in civil matters
- Citizenship of the Union
- Asylum and immigration
- External borders

EU policy-making

- Interplay between the 3 institutions
 - European Commission proposes laws and policies
 - European Parliament and Council approve or amend the law or policy



Co-decision procedure



Legal instruments

- **Regulations** - binding and directly applicable in all Member States
- **Directives** - establish binding principles but leave Member States free to decide how to achieve them
- **Decisions** - binding upon whom they are addressed
- **Opinions** and **Recommendations** - not binding but carry considerable force

EU Health Policy

- **EU Health Policy is complex**

multiple Stakeholders – patients, physicians, nurses and other allied professions

..and is becoming more so

was exclusively the domain of Member States – now EU is becoming more vocal

EU competencies in health

- **EU competence** - in public health – Amsterdam Treaty (1997) article 152
- **Article 152 states** - EU can act only to complement the activities of Member States

Article 152

- **Community action**

- Improving public health and preventing human illness and disease
- Obviating dangers to human health.

- **Action cover promoting**

- research into transmission and prevention
- health information and education

Article 152 - 4 (a)

...Shall contribute to the achievement of the objectives through adopting:

(a) Measures setting high standards of quality and safety of organs and substances of human origin, blood and blood derivatives...

EU Health Policies

- **Public Health**
 - **Initiatives in cardiovascular disease, diabetes, obesity**
- Employment and social aspects
- Environment
- Food safety
- Drugs
- Information
- **Healthcare**
 - **Blood, tissues, cells and organs**
- Development
- Mobility of Health Professionals
- Research
- Sports

Actions on diabetes and cardiovascular disease

- **Austrian Presidency** (2006) established four working groups:
 - Prevention of cardiovascular disease in diabetes
 - Disease management - reducing diabetes complications
 - Early prevention of type 2 diabetes
 - Societal and gender aspects of type 2 diabetes

The Vienna Declaration presented to Council of Health Ministers

- **European Parliament** (2007) resolution to tackle cardiovascular

DG-SANCO: EU Health Programme

- **Programme of Community Action in Public Health (2008-2013)**

€321,500 billion for activities to promote and improve health in Europe

DG-Research: Research

- **7th Framework Program for Research (FP7) 2007-2013**
 - Health theme (€ 6.1 billion)
 - Marie Curie actions (€ 4.7 billion)
- **Innovative Medicines Initiative (IMI) -**
 - Invigorate the pharmaceutical industry in Europe (€ 4.7 billion)

EKHA – immediate objectives

- Raise awareness of the CKD epidemic
- Engage the EU initiative in Transplantation
- Incorporate kidney disease in the EU public health programme
- Increase kidney research in FP7
- Respond to relevant EU initiatives

Raising Awareness

- Contacts with relevant individuals within the Commission (DG-SANCA and DG Research)
- Contacts with Presidency Health Representatives
- Establish an MEP Group on Kidney Disease
- Public Events

EU Parliament EKHA Symposium



Chronic Kidney Disease Europe's Silent Epidemic *A Wake-Up Call*

European Parliament
Room A3E-2

Tuesday 4 March 2008
15.00 - 17.00

Permanent exhibition at 3rd Floor Bar
Forum from 3 - 5 March 2008



Programme

15:00 - 17:00

Introduction

Professor Andrew Rees, *Chairman of EKHA*

European Parliament endorsement of kidney health issues

Mrs Frieda Brepoels, *MEP, EPP-ED Shadow
Rapporteur 'Organ Donation and Transplantation:
Policy Actions at EU-Level'*

The daily reality of Chronic Kidney Disease (CKD) - A patient and nurse's perspective

Valerie Twomey, *Patient*
Karen Jenkins, *European Dialysis and
Transplantation Nurses Association/European
Renal Care Association CKD Group Chair*

Incidence, consequences and economics of early detection of CKD

Paul E. de Jong, *Professor in Nephrology, University
Medical Center Groningen*

Public Health Strategies to identify CKD and to prevent its consequences (lessons from the UK and the rest of the world)

Dr. Donal J O'Donoghue *National Clinical
Director for Kidney Care, Salford Royal NHS
Foundation Trust, UK*

Roundtable discussion

17:30 Cocktail reception, Member's salon

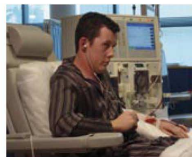
EU Parliament EKHA Symposium

- Awareness raising
- Publicity for EKHA
- Catalyst for formation of MEP Group
- Publicity material sent to all MEPs
- Short article in MEP Journal
- Instrumental in inserting an “EKHA” amendment in Adamou Report

Short article in MEP Journal

Chronic Kidney Disease Europe's Silent Epidemic

Chronic kidney disease is the general name for persistent irreversible damage to the kidney. In its earliest stages, the kidneys may only have minor structural damage and often such damage tends to progress if undetected and untreated. One of the signs of early CKD is the presence of small amounts of protein in the urine. Advanced CKD may ultimately require dialysis or kidney transplantation for survival.



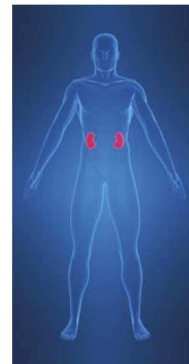
Reliable estimates suggest that at least 10% of the European population have some degree of chronic kidney disease. This means around 40 million European citizens. However, in many cases affected persons are not aware of their condition because the disease often develops without symptoms.

Moreover, the general public and policy makers are equally ignorant of its importance, which makes chronic kidney disease a "silent epidemic". In the next 10 years the number of affected citizens is set to double because chronic kidney disease is linked to other epidemics affecting Europe such as diabetes, high blood pressure and cardiovascular disease.

On the eve of World Kidney Day 2008 an MEP Group on Kidney Health Issues was created to provide a forum for experts and EU decision-makers in which to discuss EU action in the face of the current epidemic of Chronic Kidney Disease. The Group is an initiative conceived by the European Kidney Health Alliance and launched with MEP Mrs Frieda Brepoels. The European Kidney Health Alliance brings together all kidney stakeholders in Europe who work cooperatively for a European health environment in which there is a sustained decrease in kidney disease and its consequences.

Its constituent members are CEAPIR (European Kidney Patients' Federation), EDTNA/ERCA (European Dialysis and Transplant Nurses

Association/European Renal Care Association), ERA-EDTA (European Renal Association – European Dialysis and Transplant Association) and ISN (International Society of Nephrology).



For more info about EKHA or the MEP Group, please contact:
Anna Rouillard • Tel: +32 2 639 6230 • Email: secretariat@ekha.eu • www.ekha.eu



EU Parliament EKHA Symposium

- Awareness raising
- Publicity for EKHA
- Catalyst for formation of MEP Group
- Publicity material sent to all MEPs
- Short article in MEP Journal
- Instrumental in inserting an “EKHA” amendment in Adamou Report

Amendment to Adamou

*..... effective public health measures to facilitate the early detection and management of the chronic diseases that cause organ failure, such as **chronic kidney disease**, need to be introduced to minimise the number of people needing organ or kidney transplants in the future.*

EKHA initiatives– Health Policies

- Involvement in all levels of the EU consultation on transplantation
- Recommendations to EMEA consultation (Guideline on immunosuppressants for solid organ transplantation)
- Review of EUGLOREH study (upcoming)

EKHA initiatives – Research

- Discussions with Chronic Diseases officers of DG Research.
- FP7 – Call on “Molecular and cellular mechanisms in Chronic Kidney Disease” expected in next call

FP7 3rd Call Topic

- Molecular and cellular mechanisms in Chronic Kidney Disease will be one of the topics in FP7 Call 3
- Large Scale Project - €12 million over 3 or 4 years
- Project should range over mechanisms to clinical implementation

EKHA – aims for 2009

■ Awareness

- Official EU Parliamentary Group
- Parliamentary recommendation on CKD

■ DG-SANCO

- Build CKD into public health programme
- Transplantation topic for public health

■ DG –Research

- Second research topic for FP7

EKHA Summary

- EKHA has rapidly evolved into an effective organisation for promoting the cause of those with renal disease – this success is absolutely dependent on its being an Alliance of patients, health care professionals and investigators.

EKHA website (www.ekha.eu)