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!
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

- March 2006 – initial discussions
- June 2006 – initial scoping exercise
- March 2007 – draft MoU
- June 2007 – MoU signed Chair appointed
- September 2007 – work started
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

The co-decision procedure at a glance

The diagram illustrates the steps involved in the co-decision procedure:

1. **Commission's proposal** → **Parliament 1st reading** → **EP opinion to the Council**
   - **Council adopts common position by QM**
   - Approves all amendments or no EP amendments - OK

2. **EP 2nd reading: 3 months max**
   - EP amends CP
   - Rejects by absolute M

3. **Council: 3 months**
   - Council adopts common position
   - Approves all EP amendments - OK
   - No agreement

4. **Conciliation**
   - Conciliation within 6 weeks
   - Agreement
   - Both OK within 6 weeks

   **Qualitative Majority**
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

World Kidney Day
13 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 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
Chronic Kidney Disease
Europe’s Silent Epidemic

Chronic kidney disease is the general term for persistent irreversible damage to the kidneys. In its early stages, the kidneys may only have minor structural damage and often such damage tends to progress if untreated and unmonitored. Long-term exposure to this sickness may lead to further complications and the presence of small amounts of protein in the urine. Advanced CKD may ultimately require dialysis or kidney transplantation for survival.

Estimates indicate that at least 10% of the European population have some degree of chronic kidney disease. This is around 40 million European citizens. However, it is 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 a growing concern across Europe, such as diabetes, high blood pressure, and cardiovascular disease.

On the eve of World Kidney Day 2008, MEP Group on Kidney Health Issues was created to provide a forum for experts and EU decision-makers in which to discuss EU actions for the prevention and treatment of Chronic Kidney Disease. The Group was initiated through the European Kidney Health Alliance and launched with MEPs from France, Germany, England, Spain, and Italy. The European Kidney Health Alliance brings together all kidney stakeholders in Europe who work cooperatively for a European and a matching decrease in kidney disease and its consequences.

For more information about EKHA or the MEP Group, please contact: Anna Routbel - Tel: +32 2 288.815 - Email: anna.routbel@ekha.eu - www.ekha.eu
EU Parliament EKHA Symposium

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........ 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
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)