PRESIDENT’S MESSAGE

Dear IFKF Members,

All of our members and friends celebrated World Kidney Day on 14th March.

What a ‘Great Day’ once again this year.

We were aware, from the survey distributed earlier in the year, that many of our members were arranging some fantastic events and it looks like these turned out to be great successes. A selection of the events from our member foundations and a number of others from professional societies and other kidney related organisations are included in this newsletter.

A report on many more events can be found on our new WKD website and don’t forget that you can upload details of your events as well if you have not yet added them to the website. The link to the WKD website can be found on www.ifkf.com. Don’t forget to take a look at the Photo Gallery where we show a selection of your pictures that you have sent to us.

A more extensive overview and evaluation of WKD 2013 will be shared with all members after the WKD team have finalised their report.

Timur Erk, President

Topics in this Newsletter:

- World Kidney Day 2013
- World Kidney Day 2013 in the European Parliament, organized by EKHA
- Report by Charles Kernahan on the Kidney Health for Life project

You will also find latest news on our new website www.ifkf.org
1. WORLD KIDNEY DAY 2013

The theme for WKD this year was used extensively across the globe and delivered an important message.

2. WORLD KIDNEY DAY 2013 IN THE EUROPEAN PARLIAMENT, ORGANIZED BIJ EKHA

About one week before World Kidney Day the new website has been launched (www.worldkidneyday.org) This is an impression of the homepage. Building communities through social media is one of the strategies behind the new website.

Sara Martin, the project manager for WKD 2013, has written a summary report on many of the events for this year, all of which have been uploaded to the WKD website.

Malaysia:
Malaysian Society of Nephrology, and the Malaysian Ministry of Health & National Kidney Foundation: a Marathon a Cycle Race & a Carnival in Kuala Lumpur. The day was televised on national TV.

USA:
Mid Western States: In recognition of National Kidney Month and to inspire people to enjoy a healthy diet, Celebrity Chef Aaron McCargo, Jr. will tour several U.S. cities. Star of the Food Network TV show “Big Daddy’s House,” Chef McCargo will unveil four new locally inspired healthy kidney recipes and share tips for healthy eating.
Los Angeles:
UCLA is asking Twitter & Facebook friends to Put a Face to Kidney Disease by sharing patient photos, kidney blogs & kidney Facebook pages on World Kidney Day, using the hashtag #facesofkidneydisease.

United Kingdom:
In Westminster, a Parliamentary Reception was held in honour of World Kidney Day with Health Minister Anna Soubry, and National Clinical Director Dr Donal O’Donoghue.

Turkey:
TV and cinema celebrities have participated in a photo shoot which will grace billboards across the country; two airline companies will show the short video and visuals during their national flights; Carrefour supermarkets have printed visual material behind 40,000 rolls of paper receipts; National soccer teams will carry banners before the games during the entire WKD week!

Press conference with Timur Erk, President of the Turkish Kidney Foundation, and President of IFKF.

Large billboards in Istanbul streets.
Taiwan:
World Kidney Day was celebrated with a state-sponsored Health Fair and carnival in the Taipei Zoo and across the city of Taipei.

Iran:
The Esteghlal soccer team (the famous club football of Iran) and Al-Ein (from the Emirates) entered the Azadi grand stadium during the Asian football match between the two teams, holding a banner of World Kidney Day. Also, a WKD pamphlet was spread to football fans in Azadi stadium. WKD news was broadcasted by Esteghlal club.

In addition to Sara’s report above, please find our own summary of other activities.

USA: National Kidney Foundation
NKF US created a Facebook page, of which two screen shots from the Facebook page are shown below:
Morocco: FMAIRTO
The announcement of the WKD events for Morocco.

India: National Kidney Foundation
IKF India is undoubtedly one of the most active foundations in the IFKF community.

^ Kidney banner shown at events.

< Roll up banner
The European Kidney Health Alliance (EKHA) is an umbrella collaboration where patient organisations, professional societies of nephrology, charities, dialysis and transplant associations and the association of nurses, work together to present the issues of chronic kidney disease to the European Commission and the European Parliament. IFKF is a partner within the EKHA, thanks to the substantial contribution of the Dutch Kidney Foundation.

The EKHA has organised an event in the European Parliament for the last few years, comprising of a working lunch with a number of relevant presentations to the Members of European Parliament group. This group is the key communication vehicle for the kidney community to discuss matters related to chronic kidney disease and other related chronic diseases.

Please note some photos form the European Parliamentary proceedings:

A well known speaker, writer and kidney patient Per Åke Zillén from Sweden:
Prof Norbert Lameire, President of EKHA presenting key facts on chronic kidney disease.

All the presentations made during the working lunch can be downloaded from the ERA EDTA site through a link on the IFKF website. Please see the message in the rolling banner on our homepage www.ifkf.org

For more information: please visit www.worldkidneyday.org and www.ifkf.com and don’t forget these are important websites to visit again and again for new and important information.

Finally a reminder, if you want to share details about your events with others in the IFKF community, please send your information with photos to Els de Weerd at elsdeweerd@ifkfms.com

3. REPORT BY CHARLES KERNAHAN ON THE KIDNEY HEALTH FOR LIFE PROJECT

International Steering Committee Meeting
London Heathrow Sofitel, 8th and 9th March 2013
Please find below a very brief summary of the latest meeting of the International Steering Group for KH4L, an initiative supported by a small grant from Abb-Vie, the new Company formed from Abbott Pharmaceuticals.

I have recently taken over the IFKF representation from Paul Beerkens, so this was my first face to face meeting. The meeting was chaired by Dr Adeera Levin.

The objective for KH4L is to improve outcomes for CKD patients across the globe and an agreed initiative currently under way is an inventory of the status of early identification and treatment across Europe, Canada, Turkey and Israel. These markets having been agreed by the steering committee at the outset.

Each country has an identified lead and data is being collected and coordinated by the University of Alberta, Canada.

The inventory is being compiled from survey data collected from a number of stakeholders including: Patients, Nephrologists, Primary Care Physicians, Nurses and Allied Healthcare professionals and Policy makers.

A report will be compiled in the late spring or early summer, with the view to have the work published in at least one major professional journal.
We are also planning a dissemination meeting towards the end of 2013, that will be an invitee only occasion, due to budgetary constraints.

At the end of 2013 the funding from Abb-Vie will cease and we will discuss the opportunity to continue the concept in some way or another, perhaps as a joint initiative with other International representative organisations. This is not as yet the agreed future for KH4L, but we should look build on what has been a great initiative.

**Meeting Agenda:**
1. Review Objectives
2. Review Status of Inventory
3. Agree methods to increase input to Inventory
4. Agree completion timetable
5. Agree next steps
6. Discuss the future opportunities

**Agreed Actions:**
1. Members of Committee look to increase input to inventory in slow to respond markets
2. Consider recommendations on appropriate journals for publications
3. Consider and recommend venues for dissemination meeting
4. Local representatives to be contacted by steering committee to discuss local dissemination activities post report completion.
5. Committee members assist project lead to correct or modify input form certain markets and countries, where obvious misinterpretation has been noted.