



Improvement in the quality of life and quality of care for all at risk of, or suffering from, kidney disease regardless of race, ethnicity, creed, gender or social class

INVENTORY OF COUNCIL MEMBER RESOURCES FOR PATIENTS & KIDNEY HEALTHCARE PROFESSIONALS

Our Resources Inventory offers a regularly updated listing of contact information for our Members - kidney foundations, patient associations and kidney related organisations, from many corners of our globe.

IFKF Council Member organisations – Our Members represent kidney foundations, societies, associations, patient and other interest groups from around the globe. Many offer evidence based kidney health education resources specifically created to help educate patients on what they can do to improve their health, to enable them to become an ‘expert patient’. Many resources are free to download. Please contact IFKF members directly for hard copies of their information if needed. In order to keep the Inventory up to date please contact the editor Marianne Vennegoor: mavennegoor@aol.com

Copyrights: Write to the individual IFKF Council Member, to request permission to reprint any of their material should you wish to do so. The source of information should be displayed in any new material developed using the respective kidney foundation’s information. See also individual websites for the individual Member’s copyright.

Take the time to explore IFKF Council Member websites (where available) to discover what multilingual resources are available. These organisations know what’s happening locally in their kidney community and many offer resources in the local language. Some offer chat rooms, message boards, health forums, ‘kidney’ blogs and podcasts. Using these network systems also offers a window into local information. Some of our Members have active profiles on Facebook and foster online discussions via Twitter.

Kidney Foundations, patient support and advocacy groups and Professional Organisations. Committees often use blog and message board postings for updates on their news, issues around patient advocacy – organ allocation for transplant, organ donation protocols, home dialysis and transport and professional issues as appropriate. Using online phone contact (such as Skype) enables individuals to contact people from their own country and abroad to talk in their native language about complications of CKD for free. See www.ifkf.net for suggestions.

Donations. Consider making a direct donation to an IFKF organisation in your home country, to help them progress with their important work. A direct donation to the work of the IFKF will help us foster international collaboration by exchanging ideas and experience to improve the health, wellbeing and quality of life of individuals with kidney disease.

Marianne Vennegoor, Emeritus Renal Dietitian - Inventory Manager, Education Sub Committee -
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Updated 29 September 2011

ARGENTINA

BUENOS AIRES

ASOCIACION SOLIDARIA DE INSUFICIENTES RENALES

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www.rein.ca (French)

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Online and hard copy educational materials

Patient Manual: Living with kidney disease/ Vivre à sa façon
Hard copies available -English, French, Italian, Chinese, Punjabi
Also available in VHS, DVD and audio for the blind
All versions published online English & French www.kidney.ca/Page.aspx?pid=394

Wide range of brochures available www.kidney.ca/Page.aspx?pid=1361

Extensive range of fact sheets www.kidney.ca/Page.aspx?pid=1362

Study: Living with End-Stage Renal Disease (ESRD): Perspectives on
suffering & healing

www.mcgill.ca/wholepersoncare/esrdqualityofliferesearch

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New educational Information series “Guides for Patients”

Kidney Disease, Haemodialysis and Peritoneal Dialysis,
Kidney Transplantation, Thinking about Donation?
See www.ika.ie website to read the complete text of all 4 books.

ISRAEL

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IKEAJ IN COLLABORATION WITH KEEP (KIDNEY EARLY EVALUATION PROGRAM USA)

The International Kidney Evaluation Association Japan (IKEAJ) has been established in partnership with the National Kidney Foundation (NKF) of the U.S. (the lead organization in this field) to facilitate collaboration among a wide range of people so that great strides can be made toward the elimination of the problems caused by kidney disease.

IKEAJ provides a free kidney health screening program, the Kidney Early Evaluation Program, to patients affected by diabetes, hypertension, and possibly the families of those affected by kidney disease as well. If early detection of more kidney disease cases can be accomplished and, consequently, appropriate medical care is provided to them, the risks of kidney disease progressing to the point where it threatens the quality of life and future possibilities of many individuals may be dramatically minimized.

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Membership Pending

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UNITED KINGDOM

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<http://www.kidneyresearchuk.org/health/health-information.php>
includes the link to DVDs on this website -
Living with Kidney Disease (3 modules) and
Diabetes Able Project

ENGLAND

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Medical Education: www.kidneycancersymposium.com

NEW YORK

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NKF Kidney Early Evaluation Program (KEEP Healthcare)
www.kidney.org/KEEP

Free kidney health screening to raise awareness about kidney disease in high risk individuals - KEEP Healthcare provides free testing and education to prevent kidney disease and its complications can be delayed.

NKF KDOQI Guidelines www.kidney.org/professionals/KDOQI/
NKF KDIGO Guidelines www.kdigo.org
Catalogue Educational Resources www.kidney.org/professionals/KLS/catalog.cfm
A-Z OF Kidney Disease www.kidney.org/atoz Brochures online (*multilingual*)
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info@kidney.org/about/legal.cfm

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PKD Learning Center – The most comprehensive source of ADPKD and ARPKD information available <http://www.pkdcure.org/tabid/1556/Default.aspx>

PKD Webinars – Experts discuss topics about health and lifestyle issues related to PKD
<http://www.pkdcure.org/tabid/1572/Default.aspx>

KidneyLink – A website dedicated solely to kidney transplant information for all CKD patients. www.kidneylink.org

ZAMBIA

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