Kidney Health for all.
Optimal care for people with kidney disease.

IFKF-WKA Connect
1 April 2022

Official Newsletter of IFKF-WKA
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4. Forthcoming Events
A warm greetings to everyone around the world. I trust we are co-living with COVID and allowing us to refocus on “Better kidney care for everyone” and “Better care of patients with kidney disease”. This issue of IFKF-WKA Connect focuses on our communication channel and the flagship programs of IFKF-WKA.

We are sharing the World Kidney Day events by our members. We draw your attention to the importance of enhancing Health Literacy for the general public and patients with kidney disease, in particular, the role of Organization Health Literacy to provide health care information for the users, in a way that they can get, understand and use.

We are very excited to launch IFKF-WKA flagship programs - World Kidney Online, World kidney Survey & Research, World Kidney Meetings & Consensus.

World Kidney Recipes will be launched on 16th June 2022 at the 20th Congress of International Society of Renal Nutrition and Metabolism. We will be promoting “Eat Smart, Eat well” for patients with kidney disease, to bring the joy back in their eating which is an important element of living well with kidney disease.
Communication – Website

IFKF-WKA website is updated with new information
- Flagship programs, IFKF-WKA Connect, patient’s voice and story

Can select language (Auto-translation)

Flagship programs
Communication – Social Media

Facebook
https://www.facebook.com/ifkf.wka

Twitter
https://twitter.com/ifkf_wka

Instagram
https://www.instagram.com/ifkfwka/

YouTube channel
https://www.youtube.com/channel/UCGa22RzxGzQLUpbaO20ZMq Dw

Linkedin
https://www.linkedin.com/company/ifkfwka/posts/?feedView=all
Kidney health for all: bridging the gap in kidney health education and literacy

Robyn G. Langham1, Kamyar Kalantar-Zadeh2, Ann Bonner3, Alessandro Balducci4, Li-Li Hsiao5, Latha A. Kumaraswami6, Paul Laffin7, Vassilios Liakopoulos8, Gamal Saadi9, Ekmol Tantisattamo9, Ifeoma Ulasi10, and Siu-Fai Lui11 for the World Kidney Day Joint Steering Committee12

The high burden of kidney disease, global disparities in kidney care, and poor outcomes of kidney failure bring a concomitant growing burden to persons affected, their families, and carers, and the community at large. Health literacy is the degree to which persons and organizations have or equitably enable individuals to have the ability to find, understand, and use information and services to make informed health-related decisions and actions for themselves and others. Rather than viewing health literacy as a patient deficit, improving health literacy largely rests with health care providers communicating and educating effectively in codesigned partnership with those with kidney disease. For kidney policy makers, health literacy provides the imperative to shift organizations to a culture that places the person at the center of health care. The growing capability of and access to technology provides new opportunities to enhance education and awareness of kidney disease for all stakeholders. Advances in telecommunication, including social media platforms, can be leveraged to enhance persons’ and providers’ education; The World Kidney Day declares 2022 as the year of “Kidney Health for All” to promote global teamwork in advancing strategies in bridging the gap in kidney health education and literacy. Kidney organizations should work toward shifting the patient-deficit health literacy narrative to that of being the responsibility of health care providers and health policy makers. By engaging in and supporting kidney health–centered policy making, community health planning, and health literacy approaches for all, the kidney communities strive to prevent kidney diseases and enable living well with kidney disease.


https://www.dropbox.com/s/b0m5r92ecqk7swa/WKD(Editorial%20for%20all%20bridging%20gap%20in%20kidney%20health%20education%20and%20literacy).pdf?dl=0
### Webinar 1
11 a.m. CET for Europe/Africa/Asia

Welcome remarks from President IFKF-WKA (SF Lui) and ISN (Agnes Fogo)

<table>
<thead>
<tr>
<th>Patients’ Experience</th>
<th>Patients’ Experience</th>
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<tbody>
<tr>
<td>Manvir Victor, Malaysia</td>
<td>Verónica Martinez, Mexico</td>
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<tr>
<td>IFKF member and Chair of the ISN Patient Liaison Advisory Group.</td>
<td>Member of the ISN’s Patient Liaison Advisory Group</td>
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</table>

### Health Literacy
Anne Bonner, Australia

### To Connect, Be Connected
SF Lui, IFKF-WKA

### Engaging Healthcare Professionals
Beatrice Titiloba Segun-Agboola, Nephrology Nurse Educator, Nigeria.

### Advocating for Better Kidney Health
Paul Laffin, Northern Ireland.

Moderated Q&A (live)

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Link to the recording of the Webinar:
[https://academy.theisn.org/2021/Webinars/351406/faculty.presenter28s29.world.kidney.day.2022.bridge.the.knowledge.gap.to.better.html?f=menu%3D32*browseby%3D8*sortby%3D2*media%3D30*label%3D24297](https://academy.theisn.org/2021/Webinars/351406/faculty.presenter28s29.world.kidney.day.2022.bridge.the.knowledge.gap.to.better.html?f=menu%3D32*browseby%3D8*sortby%3D2*media%3D30*label%3D24297)
To connect, Be connected.

Siu-Fai Lui  BBS MH JP
- Co-Program Director, World Kidney Day Steering Committee
- Chairman, Hong Kong Kidney Foundation.

https://www.dropbox.com/s/z4odim0sqo7qsfn/WKD22_Webinar%20IFKWKA%20ISN_Lui%2020v220308.pdf?dl=0

Bridging the Knowledge Gap to Better Kidney Care

Importance of Health Literacy

Prof Ann Bonner
School of Nursing & Midwifery, Griffith University, Australia

https://www.dropbox.com/s/z4z9bmtcd69hd2i/WKD22_Webinar_AnnBonner%20HealthLiteracy.pdf?dl=0
See appendix 1 for full report
Webinars conducted by IFKF-WKA or in conjunction with other organizations are posted on IFKF-WKA website (World Kidney Online) for open access.
Pros and Cons of Plant based diet for Chronic Kidney Disease

(link to the webinar – will be available soon)
The 2nd TANKER & IFKF-WKA CME

You're Invited!

Date: Saturday 23rd April 2022
Time: 6:30 pm IST

Dr. N. GOPALAKRISHNAN
"Kidney Transplant"

ORGANIZED BY:
TANKER Foundation & International Federation of Kidney Foundations – World Kidney Alliance (IFKF-WKA)

Dr. ARPANA IYENGAR
"Kidney Transplant in Children"

https://youtu.be/57p4Cr9_4tU
Proposal - To improve health literacy
Set up “Kidney Online”

• Member organization to seek partnership with local societies (nephrologist, renal nurses) to conduct webinars for patients and general public.

• Our WKD survey clearly indicated patient prefer to have the information from healthcare professionals.

• A need to facilitate a platform for patient/citizen to FIND the information, in a way that they can UNDERSTAND, if so, more likely to USE (adopt)
Kidneys Talk” for Everyone

<table>
<thead>
<tr>
<th>Fortnightly</th>
<th>Topic</th>
<th>Title of the talk</th>
<th>Guest speakers</th>
<th>Hosts</th>
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<tbody>
<tr>
<td>5 October 2021</td>
<td>Kidney and you</td>
<td>Kidney and Kidney disease</td>
<td>Dr. SL Lui</td>
<td>Ms. Maggie Ng</td>
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<td></td>
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<td>Dr. Vincent Chow</td>
<td>Dr. KF Chau</td>
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<tr>
<td>19 October 2021</td>
<td>Kidney disease and you</td>
<td>Your kidneys are not well, you need to know!</td>
<td>Dr. Sunny Wong</td>
<td>Ms. Candy Chea</td>
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<td>Dr. William Lee</td>
<td>Dr. Samuel Fung</td>
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<td>2 November 2021</td>
<td>Kidney failure and you</td>
<td>At the crossroad of kidney replacement therapy.</td>
<td>Dr. SF Lui</td>
<td>Dr. KF Chau</td>
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<td>Dr. YL Cheng</td>
<td>Ms. Windy Lee</td>
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<tr>
<td>14 November 2021</td>
<td>Kidney Replacement therapy 1: Peritoneal dialysis</td>
<td>The myth of peritoneal dialysis</td>
<td>Dr. CK Chan</td>
<td>Ms. Maggie Ng</td>
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<td>Ms. Sandy Hui (nurse)</td>
<td>Ms. Windy Lee</td>
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<td>30 November 2021</td>
<td>Kidney Replacement therapy 2. Haemodialysis</td>
<td>The concerns on haemodialysis</td>
<td>Dr. Maggie Mok</td>
<td>Dr. Samuel Fung</td>
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<td>Ms. Janet Li (nurse)</td>
<td>Ms. Maggie Lee</td>
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<td>Dr. Winston Fung</td>
<td>Prof Sydney Tang</td>
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<td>28 December 2021</td>
<td>Rehabilitation 1</td>
<td>Barrier free renal replacement therapy</td>
<td>Dr. Lorraine Kwan</td>
<td>Dr. KF Chau</td>
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<td>Dr. Jack Ng</td>
<td>Dr. YL Cheng</td>
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<tr>
<td>11 January 2022</td>
<td>Rehabilitation 2</td>
<td>Living well with kidney disease</td>
<td>Ms. Sabrina Mok (dietitian)</td>
<td>Dr. Samuel Fung</td>
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<td>Ms. Maki Mak (MSW)</td>
<td>Ms. Maggie Lee</td>
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<tr>
<td>24 January 2022</td>
<td>Rehabilitation 3</td>
<td>Walk with you (support)</td>
<td>Dr. John Chan</td>
<td>Dr. KF Chau</td>
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<td>Ms. Dora Leung (nurse)</td>
<td>Dr. CY Yung</td>
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**Push and Pull approach**

- **Push** – live webinar
- **Pull** – can be viewed and time, anywhere

Live webinar (45 minutes) fortnightly on Zoom, broadcast via Facebook, YouTube Channel.
Host by Hong Kong Kidney Foundation, Hong Kong Society of Nephrology, Hong Kong Association of Renal Nurses
Viewed 8,400 on FB, 16,000 on YouTube, 8 million time via secondly posting on Newspaper website
English version of the PowerPoint is available online. [https://hkkf.org.hk/kidneystalk/](https://hkkf.org.hk/kidneystalk/)
World Kidney Survey & Research

World Kidney Survey

A pilot survey by IFKF-WKA
Access to healthcare information
by the kidney patients
Jan-Feb 2022

See appendix 2 for full report


World Kidney Survey

Living well with kidney disease
Patient engagement: What matters to patients

Read More

Setting up an International Panel
To initiate and coordinate
Worldwide survey & research

20 Jan 2022, 23 Mar 2022
Graeme Smith, Ann Bonner, Kam Kalanta, SF Lui

**Survey:** WKD survey on Access to healthcare information

**Research:** International research projects on Health Literacy
World Kidney Recipes

World Kidney Recipes will be launched on 16 June 2022 at the Special session during the 20th Congress of International Society of Renal Nutrition and Metabolism.
World Kidney Publications

Perspectives

Patient-centred approaches for the management of unpleasant symptoms in kidney disease


The management of chronic kidney disease (CKD) includes severe or frequent unpleasant symptoms. Some patients may benefit from interventions to manage these symptoms, but others may not. Several research articles have emphasized the importance of patient-centred care in managing unpleasant symptoms, but little is known about how patients, healthcare providers, and stakeholders prioritize unpleasant symptoms for management. The current study aimed to examine the perspectives of patients, healthcare providers, and stakeholders on unpleasant symptoms and their management.

The study was a qualitative research study that used focus group methods. Focus groups were conducted with patients with CKD, healthcare providers, and stakeholders. The focus groups were audio-recorded, transcribed, and analyzed using thematic analysis.

The results indicated that patients, healthcare providers, and stakeholders had different priorities for unpleasant symptoms and their management. Patients prioritized symptoms that were more bothersome or limiting, while healthcare providers prioritized symptoms that were more severe or likely to cause harm. Stakeholders prioritized symptoms that were more socially or economically burdensome.

The study concluded that patient-centred approaches for the management of unpleasant symptoms should be developed to meet the needs of patients, healthcare providers, and stakeholders. Further research is needed to develop effective strategies for managing unpleasant symptoms in CKD.
Special Session
IFKF-WKA Worfld Kidney Recipes
Thursday 16 June 2022  20:00-21:15 pm

Registration:  https://isrn2022.sciconf.cn/