



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

IFKF-WKA Connect
January 2021
Official Newsletter of IFKF-WKA

IFKF-WKA Connect

Jan 2021

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Editorial Board

Ms. L Kumaraswami

Ms. A Onat

Ms. E Obeng

Mr. Tashi Namgay

Dr. SF Lui



President's
message

PRESIDENT'S MESSAGE

Dr. Siu-Fai Lui, BBS MH JP.

President,
International Federation of Kidney Foundations – World Kidney Alliance.



Welcome to the first issue of IFKF-WKA newsletter.

International Federation of Kidney Foundation was relaunched as **International Federation of Kidney Foundation – World Kidney Alliance** (IFKF-WKA) on 1 July 2020. IFKF-WKA is a renal community beyond kidney foundations, we are extending our partnership with patient group, association and organisation in the kidney field.

We have a revised vision – Better kidney health for all and Optimal care for people with kidney disease. We have a range of flagship programs, including (i) early identification of renal disease, (ii) patient engagement and partnership and (iii) renal nutrition, diet and a world kidney recipe.

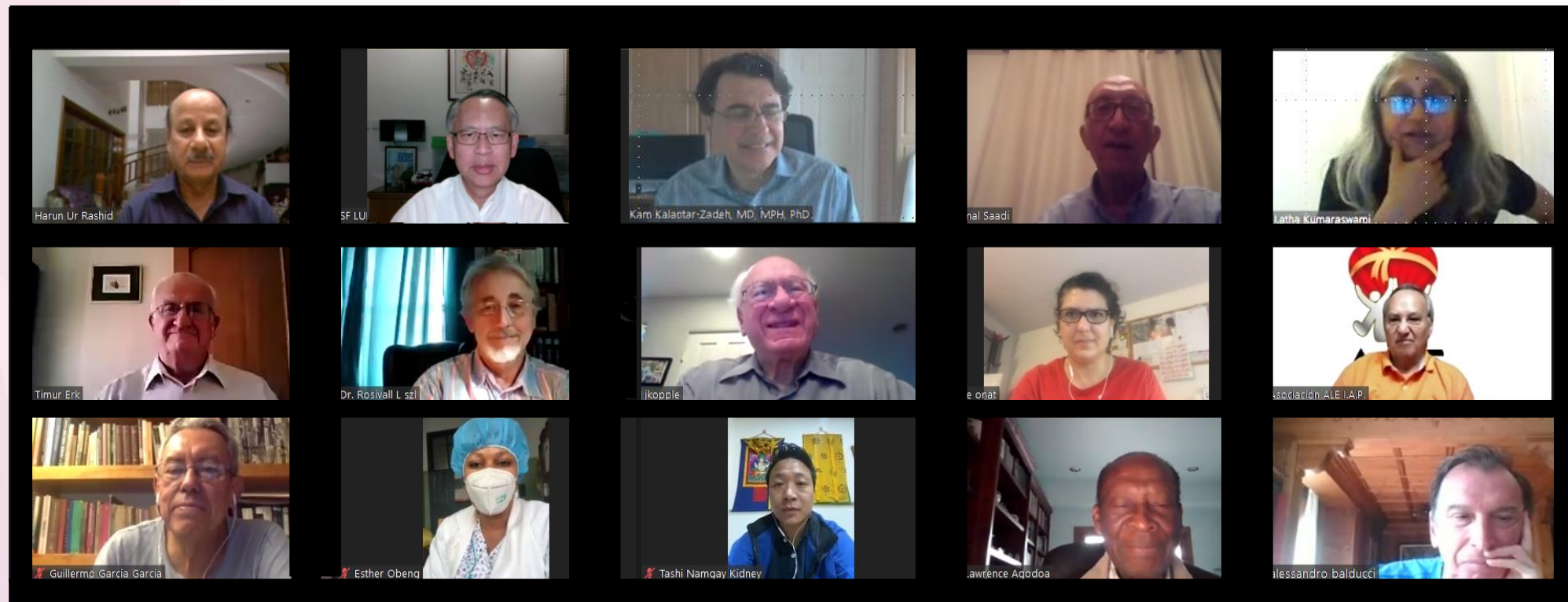
We welcome new members to join IFKF-WKA. We look forward to our ex-members re-joining the new IFKF-WKA. We believe everyone has something to contribute, to share and to learn from each others. **Let's work together for better kidney health for all, and better care for patients with kidney disease.**

SF Lui.



IFKF-WKA
Virtual launch
1 July 2020

International Federation of Kidney Foundations – World Kidney Alliance Virtual launch on Zoom call-conference 1 July 2020



Elizabeth Myles, Zaki Morad, Marianne Vennegoor, Fanie du Toit



Vision
Mission
Strategy

Vision

Better kidney health for all.

Optimal care for people affected with Kidney Disease / Failure.

Mission To leading a worldwide movement to

- Promote better kidney health with primary, secondary and tertiary preventive measures.
- Promote optimal treatment and care so as to maximize the health, quality of life, and longevity for people with or at high risk for developing kidney disease / failure.

Strategy A worldwide renal Community

- To establish an international community and a network for people and organizations who are committed to improving the health and care of people with or at high risk for developing Kidney Disease or Kidney Failure.
- To act as a global advocate for issues related to Kidney Health and Kidney Disease.
- To partner with stakeholders, healthcare professionals, interested people, including patients and patient advocacy groups and related organizations worldwide.
- To co-design, co-produce programs and projects with stakeholders.
- To share expertise, experience, knowledge and resources.
- To advocate and promote an effective, efficient and high-quality healthcare system across the world for the prevention and care of patients with or at high risk for developing Kidney disease or Kidney failure
- To promote patient-centred care, patient engagement and empowerment.
- To promote and conduct World Kidney Day activities.
- To promote education programs worldwide.
- To promote research concerning the kidney, disease and the care of kidney patients.



Council
Advisors

Council members (2020-2021)

Dr. SF Lui, BBS. MH. JP (Hong Kong) – President

Prof. Kam Kalantar-Zadeh MD (USA) – Past-President

Ms. Latha Kumaraswami (India) – President-Elect

Mr. Carlos Castro (Mexico)

Dato Dr. Zaki Morad (Malaysia)

Dr. Alessandro Balducci (Italy)

Ms. Ayşe Onat (Turkey)

Ms. Esther Obeng (Ghana)

Mr. Tashi Namgay (Bhutan)

Dr. Ágnes Haris (Hungary)

Prof. Harun Ur Rashid (Bangladesh)

Co-opted members (past presidents)

Joel Kopple (USA), Guillermo Garcia Garcia,(Mexico), Gamal Saadi (Egypt)

Senior Advisors

Timur Erk (Turkey), Professor Loreto Gesualdo, Dr. Laszlo Rosivall (Hungary)

Advisors

Lawrence Agodoa, MD, (USA/NIH), Allison Tong (Australia)

Committees

Committees

<u>Executive</u>	<u>Membership and Council</u>	<u>Finance and Fundraising</u>	<u>Communication and Outreach</u>	<u>Education and Publication</u>	<u>Programs</u>
SF Lui	SF Lui	SF Lui	SF Lui	SF Lui	SF Lui
L Kumaraswami	L Kumaraswami	L Kumaraswami	L Kumaraswami	L Kumaraswami	L Kumaraswami
K Kalantar	K Kalantar	K Kalantar	A Onat	K Kalantar	K Kalantar
C Castro	A Balducci	C Castro	E Obeng	A Balducci	Z Morad
Z Morad	<i>G Garcia</i>	Z Morad	Tashi Namgay	A Onat	E Obeng
A Balducci	<i>J Kopple</i>	<i>G Garcia</i>		Ágnes Haris	Ágnes Haris
<i>G Saadi</i>	<i>G Saadi</i>	<i>J Kopple</i>		Harun Rashid	Harun Rashid
		<i>G Saadi</i>			Tashi Namgay

In Bold = Convenors



Annual General Meeting
12 December 2020

12 December 2020

Annual General Meeting

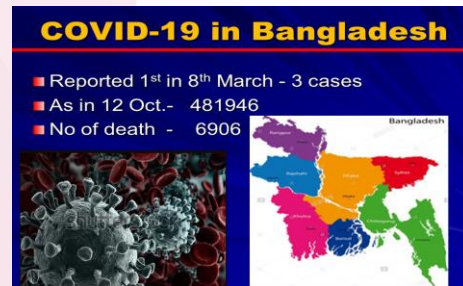


[Annual report 2020](#)

Annual Meeting

Co-living with COVID-19

Sharing of experience



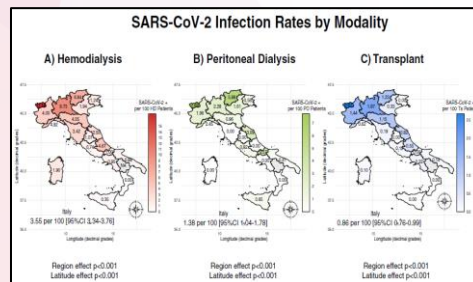
Bangladesh [Presentation](#)
Prof. Harun Ur Rashid



Hong Kong [Presentation](#)
Dr. Siu-Fai Lui



India [Presentation](#)
Ms. Latha Kumaraswami



Italy [Presentation](#)
Dr. Alessandro Balducci



Malaysia [Presentation](#)
Dato Dr. Zaki Morad

Sharing from Turkey

Turkey's Covid struggle headlines are as follows:

First case was declared on March 11, 2020, just on the eve of World Kidney Day.

So far 27.5 million people were tested by Turkish Ministry of Health. Turkey have had 2.4 million Covid cases. 24.161 people died as of today and approximately 2.3 million people recovered.

Turkey possesses significantly higher number of hospital beds and intensive care units compared with many other countries in the World. During first wave between March and June 2020 and second wave of this recent fall-winter period, we have managed to take good care of infected patients thanks to dedicated health professionals and our equipment and medicine inventory.

Turkey [Presentation](#)



Kidney Foundation Symposium Promotion of Kidney Health and Better Care of Patients with Kidney Disease – International and Asian Perspectives

Nutritional & Conservative Management of CKD in COVID Pandemic

Prof. Kamyar KALANTAR-ZADEH (United States) <https://youtu.be/Zpcnl20PYwA>

Better Kidney Health for All and Better Care and Quality of Life for People
Affected by Kidney Disease - Hong Kong Kidney Foundation

Prof. Siu-Fai LUI (Hong Kong) <https://youtu.be/LwXBbFq0h98>

Promotion of Kidney Health and Better Care of Patients with Kidney Disease,
a Collaborative Effort Between Ministry of Health, Professional Societies and
Non-Governmental Organizations – The Malaysian Experience

Dr. Zaki MORAD (Malaysia) <https://youtu.be/bYTkrBdtV8w>

Better Kidney Health for All and Better Care and Quality of Life
for People affected by Kidney Disease - India Tanker Foundation

Dr. Latha KUMARASWAMI (India) <https://youtu.be/fd2Bzamdz-4>





ASOT & ETS
Congress
21 January 2021



2nd ASOT & 6th Annual Congress of The Egyptian Transplantation Society (ETS)
in Collaboration with TTS, IPTA, MESOT, and IFKF
with Contribution of the DTI, NOTIFY, OSCE, AFRAN, Kidney academy and AFNNA
Under Patronage of his excellency prime minister Dr Mostafa Madbouly
Theme: Challenges and Updates in Transplantation
Grand Nile Tower - Qasr EINil – Cairo 20th - 22nd January 2021



Plenary (1): IFKF

Better kidney Health for all,
Better care of patients with kidney disease.
Siu-Fai Lui (Hong Kong)

[Presentation](#)

Symposium - A Kidney: Updated tools in education & patient management (Kidney Academy & IFKF)

World Kidney Recipe for Kidney Health
Kamyar Kalantar Zadeh (USA)

[Presentation](#)

Publication

Paper



SCIENTIFIC REPORTS AND GUIDELINES

Hepatitis C virus infection and global kidney health: the consensus proceedings of the International Federation of Kidney Foundations

Garnal Saadi¹, Kamyar Kalantar-Zadeh², Piero Almasio³, Gloria Ashuntantang⁴, Rashad Barsoum¹, Annette Bruchfeld⁵, Wahid Doss⁶, Hussein ElFishawy⁷, Maissa El Razky⁷, Magdy El-Serafy⁷, Fabrizio Fabrizi⁸, Hani Hafez¹, May Hassaballa¹, Mona MR Hammady¹, Hussein Sheishaa⁹, Tarek S Abdelaziz¹, Ifeoma Ulasi¹⁰, Elena Zakharova¹¹, Michel Jadoul¹²

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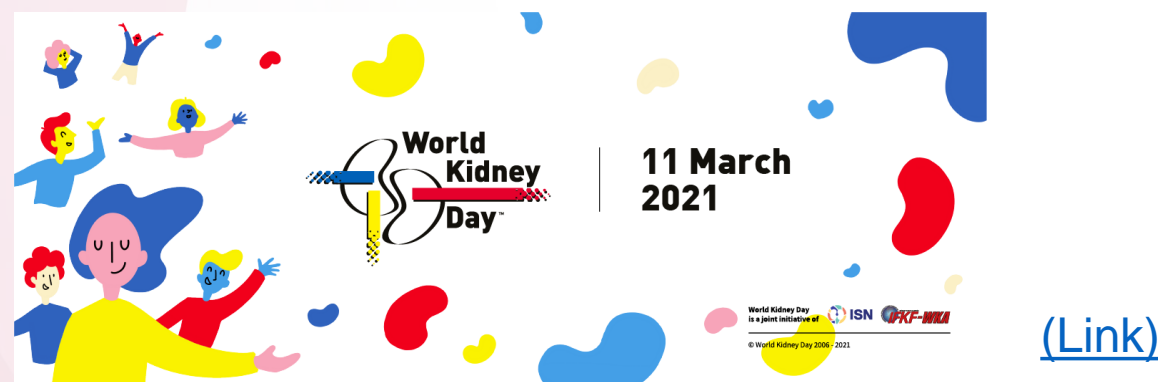
ABSTRACT

Hepatitis C virus (HCV) infection is an important cause of major morbidities including chronic liver disease, liver cancer, acute kidney injury and chronic kidney disease (CKD). Among patients with kidney disease who have HCV infection, the clinical outcomes are worse. The prevalence of HCV infection is exceptionally high among dialysis and kidney transplant patients throughout the globe. It is estimated that 5% to 25% or more of dialysis-dependent patients are affected. Almost half of all deaths in CKD patients, including HCV-infected patients, are due to cardiovascular disease, and HCV-infected patients have higher mortality. Given the importance and impact of the HCV epidemic on global kidney health, and the status of Egypt as the nation with the highest prevalence of HCV infection in the world along with its initiatives to eradicate HCV, the International Federation of Kidney Foundations convened a consensus conference in Cairo in December 2017. This article reflects the opinions and recommendations of the contributing experts and reiterates that, with the current availability of highly effective and well tolerated pharmacotherapy, CKD patients should be given priority for the treatment of HCV, as an important step towards the World Health Organization's goal of eliminating viral hepatitis as a public health problem by 2030.

Keywords: hepatitis C virus infection; Africa; chronic kidney disease.

Forthcoming event

11 March 2021



The World Kidney Day Steering Committee calls for the inclusion of life participation as a key focus in the care of patients with CKD and as a building block towards delivering the ultimate goal of living well with kidney disease. Patients with CKD and their family members or other care-partners should be **empowered** to achieve the health outcomes and life goals that are meaningful and important to them. This will require patients to understand their role, to have the necessary knowledge to be able to engage with clinicians in shared decision-making, as well as developing the skills and support for effective self-management.

We further advocate for strengthened **partnership** with patients in the development, implementation and evaluation of interventions for practice and policy settings, that enable patients to live well. This needs to be supported by consistent, accessible and meaningful communication.

We also call for greater emphasis on a **strengths-based approach** which encompasses strategies to support patient resilience, harness social connections, build patient awareness and knowledge, facilitate access to support, and establish confidence and control in self-management.

We call for more effective and more integrated and holistic **symptom management** for all patients with kidney disease beyond traditional kidney therapies including effective strategies to identify and manage symptoms that cause suffering including pain, sleep issues, anxiety, depression, stress, mobility, frailty, and others and ask for more education and management strategies to alleviate these symptoms so that patients and their care-partners can have a better health-related quality of life.

Two worldwide Webinar on “Living well with kidney Disease” will be held on 11 March 2021. Further information will be announced.



Forthcoming
IFKF-WKA
programs

Flagship
program 1

1. Living well with kidney disease

(a) World Kidney Day Steering committee

Editorial for Kidney International and 30 others journals

A worldwide webinar on 11 March 2021.

(b) A questionnaire for patient to conduct a self-assessment and reflection (Patient engagement).

A patient survey on Living well with kidney disease.

(a contributed by Hong Kong Kidney Foundation and Hong Kong Society of Nephrology and Hong Kong Association of Renal Nurses)

(c) Other publications on living well with kidney disease

A questionnaire for patient to conduct a self-assessment and reflection

Online survey Google-form



LIVING WELL WITH KIDNEY DISEASE

*Required

Q1. I am a patient *

- With chronic kidney disease, not on renal replacement therapy
- On In-centre Haemodialysis
- On Home Haemodialysis
- On Continuous Ambulatory peritoneal dialysis (CAPD)
- On Automated peritoneal dialysis (APD)
- With kidney transplantation

Q2. My own assessment of I am living well with kidney disease? 1= not well, 10 (very well) *

1 2 3 4 5 6 7 8 9 10

Not well Very well

Next

Q3(a) I have (or concerned with) the following problems which are affecting me from living well with kidney disease? *Physical (can choose more than one item)

- a1. Fatigue
- a2. Mobility
- a3. Pain
- a4. Shortness of breath
- a5. Poor appetite/Gastrointestinal symptoms
- a6. Thirsty/fluid restriction
- a7. Cramp
- a8. Restless legs
- a9. Pruritus (itchiness)
- a10. Sleep problems
- a11. Cognitive impairment
- a12. Other (please describe) *Physical

Your answer

Q3(b) I have (or concerned with) the following problems which are affecting me from living well with kidney disease? *Psychological (can choose more than one item)

- b1. Stress
- b2. Anxiety
- b3. Depression
- b4. Concern about when will need to start dialysis
- b5. Concern rejection of the transplanted kidney
- b6. Concern about the future
- b7. Other (please describe) *Psychological

Q3(c). I have (or concerned with) the following problems which are affecting me from living well with kidney disease? *Life impact (can choose more than one item)

- c1. Ability to work
- c2. Ability to study
- c3. Ability to travel
- c4. Impact on family and friends
- c5. Financial impact
- c6. Dialysis-free-time
- c7. Diet restriction
- c8. Lifestyle changes
- c9. Social activities
- c10. Other (please describe) *Rehabilitation/Financial/Social

Q4. Of the items, I have chosen for Question 3 a-c, the top 3 items that matter most to me to live well with kidney disease are? *

- a1. Fatigue
- a2. Mobility
- a3. Pain
- a4. Shortness of breath
- a5. Poor appetite/Gastrointestinal symptoms
- a6. Thirsty/fluid restriction
- a7. Cramp
- a8. Restless legs
- a9. Pruritus (itchiness)
- a10. Sleep problems
- a11. Cognitive impairment
- a12. Others * Physical
- b1. Stress
- b2. Anxiety
- b3. Depression
- b4. Concern about when will need to start dialysis
- b5. Concern rejection of the transplanted kidney
- b6. Concern about the future
- b7. Others *Psychological
- c1. Ability to work
- c2. Ability to study
- c3. Ability to travel
- c4. Impact on family and friends
- c5. Financial impact
- c6. Dialysis -free-time
- c7. Diet restriction
- c8. Lifestyle changes
- c9. Social activities
- c10. Others *Life impact

! This is a required question

Q5. What I can do for myself to live well with kidney disease? (can choose more than one item)

- a. Take better care of myself: manage the underlying disease (such as hypertension, diabetes) to prevent complications
- b. Comply with medical advice, including medication
- c. Comply with dialysis treatment as instructed
- d. Understand my illness and treatment, take part in self-care.
- e. Willing to be empowered for self-care
- f. Keep fit with exercise
- g. Eat smart, eat well
- h. Watch body weight (not overweight, or underweight)
- i. Self-reflection and sharing with others (family, friends)
- j. Make plan for the future days
- k. Others (please describe in the below)
- Other: _____

Q6. What others can do to help me &/or what options I wish I could have to live well with kidney disease? (list up to 3 items)

Your answer

Back Submit

If your organization is interested to use this questionnaire/survey form, please contact luisf@luisf.org



Forthcoming
IFKF-WKA
programs

Flagship
program 2

2. Renal nutrition, diet and a World Kidney Recipe

Eat smart, eat well

– for better kidney health and patient wellbeing.

(a) Renal Nutrition and Diet

– Healthcare professional corner.

(b) ABC of Renal Nutrition and Diet

– Patient corner

(c) World Kidney Recipe

– A collection of recipe from around the world.

Bring back the joy of eating for our patients.

3. Better kidney health for all

- (a) Early detection, early treatment
Identify people at risk (on-line quiz)
- (b) Optimise the care of patient with diabetes and hypertension (to prevent/ slow down the deterioration of kidney function).
- (c) A focus on primary prevention
- obesity and hypertension.



Forthcoming
IFKF-WKA
programs

Other programs

4. Partnership with patients
 - Information for patient.
 - Sharing of patient stories.
5. Bright ideas and Expert corner.
6. Support for foundation and patient group.
7. Webinar/ meetings.
 - Consensus meeting, topic conference.
8. Awards



Membership Fee

Application information and form

We warmly welcome new member to join us.
Let's work together for better kidney health for all,
and better care for patients with kidney disease.

Membership fee for 1 Jan 2021 - 30 June 2022 (18 months)

Organisation member			
Level 1	Full fee	High-income economies	US\$675
Level 2	25% reduction	Upper-middle economies	US\$506
Level 3	50% reduction	Lower-middle income economies	US\$338
Level 4	75% reduction	Low-income economies	US\$169
Level 5	95% reduction	Exception situation*.	US\$34
Associate member			
Level 1	Full fee	High-income economies	US\$68
Level 2	40% reduction	Others	US\$40

Application – information ([download file](#))

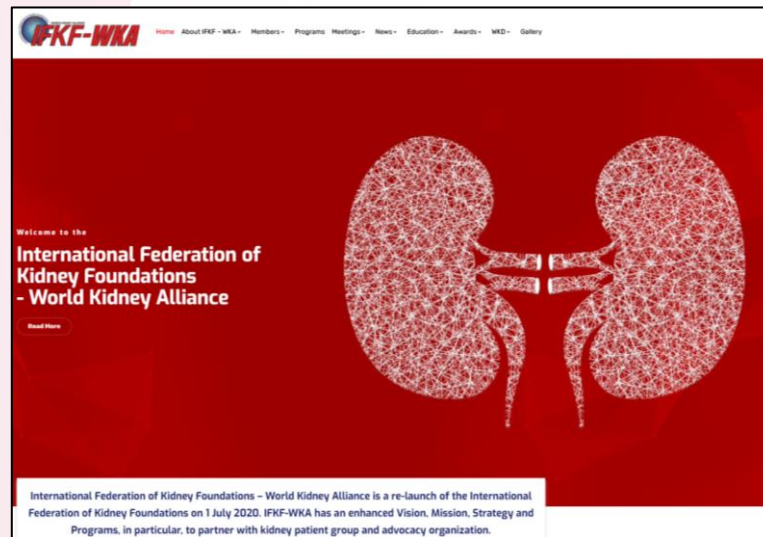
Application form ([download file](#))

*Can request special consideration for waiving of membership



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Contact

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Mexico, CDMX, 11000



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