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

IFKF-WKA Connect
Issue 3: July 2021
Official Newsletter of IFKF-WKA
IFKF-WKA Connect  July 2021

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Ms. A Onat
Ms. E Obeng
Mr. Tashi Namgay
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PRESIDENT’S MESSAGE

Dr. Siu-Fai Lui, BBS MH JP.

Welcome to the third issue of the IFKF-WKA newsletter (July 2021). Covid-19 is still causing havoc around the world, be it the situation has improved with the vaccination program. Many countries are now co-living with COVID-19. The end-game is still not clear.

We welcome Fundanier (Guatemala), Hong Kong Transplant Sports Association (Hong Kong), Al shafaqa Institution for care of renal failure and cancer patients (Yemen) and Priscilla Kapungu Kidney Foundation (Zimbabwe) joining IFKF-WKA.

The recent focus of IFKF-WKA was to set up a joint project with the International Society of Renal Nutrition and Metabolism. We believe the patient can “Eat Smart and Eat Well”. By doing so, “Long live the kidneys and patients”. This is an important element of “Living well with Kidney Disease”. The project has three components: (1) engage healthcare professionals to focus more on renal nutrition and diet, (2) engage patients to take a greater role in their diet, enhance their knowledge on renal diet and skill set in cooking and (3) setting up a World Kidney Recipes – a collection of interesting and classic recipes from worldwide that a patient can opt for within the renal diet they are prescribed. We invite member organizations to submit kidney-friendly recipes to us, for processing and posting on IFKF-WKA website.

Keep up the vigilance for COVID-19. Keep well.

SF Lui
1. IFKF-WKA has appointed Mrs. Kausalaya Padmanabhan as Hon. Manager. We are grateful to TANKER Foundation for all support in this regard.

2. IFKF-WKA will host a series of Webinars for patient education and healthcare professionals, some in conjunction with member organizations. The first webinar will be organised by TANKER Foundation & MOHAN Foundation on 18 August 2021. The topic is “Healthy Diet For Healthy Kidneys”.

3. The Facebook page name has been updated as https://www.facebook.com/ifkf.wka/

4. The YouTube channel for IFKF-WKA is IFKF-WKA Official.

5. A Zoom Room have been established for IFKF-KWA.

6. A new Official Mail Id to be used for the Secretariat: info@ifkf.org

7. New members have joined IFKF-WKA. We are grateful to our President for setting up the US$ 5000/- Membership Support Fund.
3. IFKF-WKA & ISRNM Webinar
16 June 2021

Title: Joint Webinar of ISRNM with IFKF-WKA: World Kidney Day 2021 Theme – Living Well with Kidney Disease

Live presentation followed by Live Q and A

Time Duration: 30-min presentation + 15-min live discussion

Presenter:

Dr. Lui Siu-Fai
BBS, MH, JP
President, International Federation of Kidney Foundations - World Kidney Alliance
Chairman, Hong Kong Kidney Foundation,
Co-program director, World Kidney Day Joint Steering Committee.

The Same Talk is Scheduled to be Presented by Our Speaker in Two Different Time Sessions to Facilitate a Global Participation

**Both registration links work for all countries**

1st Session
- Date: 16 June 2021
- Time: 6pm HKT, 7pm AEDT (Sydney), 10am CEST, 1am EDT (LA), 6am EDT (NY)
- Moderator: Dr. Angela Yee-Moon Wang

2nd Session
- Date: 16 June 2021
- Time: 11am HKT, 1am AEDT (Sydney), 4am CEST, 9am EDT (LA), 4am EDT (NY)
- Moderator: Dr. Joel D. Koppie

Link to Presentation by Dr. SF Lui
World Kidney Day 2021 Theme - Living well with kidney disease
Joint Steering Committee of International Federation of Kidney Foundations – World Kidney Alliance and International Society of Renal Nutrition and Metabolism on Renal nutrition, Diet and World Kidney Recipes

The first Joint Steering Committee meeting was held on 30th July 2021.

**IFKF-WKA**
- SF Lui (Hong Kong) *Co-Convenor*
- Kam Kalanta (US)
- Ágnes Haris (Hungarian Kidney Foundation)
- Carlos Castro* (ALE, IAP/FEMETRE, Mexico)
- Joel Kopple (US)
- Latha Kumaraswami* (India Tanker Foundation)
- Esther Obeng (Ghana Kidney Foundation)
- Ayşe Onat* (Turkey Kidney Foundation) *non-medical*

**ISRNM**
- Angela Wang (Hong Kong) *Co-Convenor*
- Russ Price (US)
- Anna Laura Fantuzzi (*Dietitian – Italy)
- Brandon Kistler (*Dietitian – US)
- Csaba Kovesdy (US)
- Kelly Lambert (*Dietitian - Australia)
- Denise Mafra (*Dietitian - Brazil)
- Keiichi Sumida (*Dietitian)

+ 2-4 patients as co-opted members
Purpose: To promote Long live kidneys and patients

3 inter-related components

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<td>Engage healthcare professionals and organizations</td>
<td>For patient and family</td>
<td>Patient engagement</td>
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A series of focus group and webinars will be set up for healthcare professionals and patient groups.
World Kidney Recipes (to be launched soon)

- A collection of vetted and classified recipes from around the world that is kidney-friendly and good for general health.

- Base on the diet prescription by his/her doctor/dietitian (on the amount of protein/ sodium/ potassium/ phosphate per day that he/she should take a day), a patient can select from the World Kidney Recipes what he/she would like to eat, taking into consideration the amount of protein/ sodium/ potassium/ phosphate for a portion of the food mentioned in the recipe.

- Positive eating rather than restrictive
  Bring the joy back in eating for a patient with kidney disease.

- Co-design and co-produce with patients

  Member organisations are invited to submit 5-10 classic national recipes

  - Fun and joy from cooking.
  - Appetizing, tasty, appealing and interest food
  - Creative, fusion, mix and match
  - Exchange, substitute,…
  - Use of herb
  - Cooking technique
  - Home cooking, family cooking
  - Eating out
Kam Kalanta has successful negotiated for a new section entitled “World Kidney Health” to be incorporated by Nephron, a world-leading nephrology journal by Karger.

The section aims to cover a broad range of global kidney health related issues from kidney health and kidney pathologies, to issues related to patients with kidney disease, patient centredness and patient care, prevention and management of kidney disease, healthcare environment and public health policy pertaining to kidney disease.

The Section will publish clinical research, patient-reported outcomes, consensus statements and position papers from International Federation of Kidney Foundation –World Kidney Alliance or other Kendy patient organizations.

Through World Kidney Health, Nephron will also serve as a platform to share the experiences and opinions of patients themselves or their caregivers and care-partners.
Kidney Foundation Bangladesh

From The Chairman Of the Editorial Board

It is indeed a great occasion for us that we are going to publish a Newsletter from Kidney Foundation Hospital and Research Institute, Dhaka, Bangladesh. The Kidney Foundation of Bangladesh, was established in July 2022. The aim and objective was to establish a hospital that could give treatment for patients with kidney diseases and kidney failure at affordable price. The hospital was started in October 2003, with only US$ 1000 in a rented building in Dhanmondi, Dhaka. With dedication and hard work of people involved with Kidney Foundation, it is now the largest hospital and institute for kidney and urological diseases, for dialysis and kidney transplantation.

This is now a 300 bedded hospital with 110 dialysis machines. We are performing kidney transplants weekly, home dialysis called CAPD all at an affordable price and free of cost for patients.

The hospital runs higher training on renal nursing and renal nutrition. We conduct original research in collaboration with institutes at home and abroad. This is the only ISN Sister Renal Centre in the country. We also organise conferences and training programmes in collaboration with Korea University Anam Hospital, (South Korea) and Royal London hospital (UK).
It is now high time to publish a newsletter from this institution to disseminate recent knowledge doctors, nurses, and patients at home and abroad. The first issue will cover different aspects of COVID 19 infection, including management of COVID 19 infection in patients infection in patients with chronic kidney disease, glomerulonephritis, dialysis and transplantation, and the impact of COVID on the kidney. Also we will talk on the update of the COVID -19 vaccination.

https://drive.google.com/file/d/1WdfQCTeyC3ET7ivMCUAROCcXh4CgorDb/view?usp=sharing
Kidney Community Kitchen website

Grocery shopping, label reading, and preparing renal-friendly meals can seem like a full-time job. The Kidney Community Kitchen website was created thanks to a generous bequest from a person with kidney disease who felt a dedicated website of renal-friendly recipes and related content would be beneficial for others with the disease.

The goal of the Kidney Community Kitchen is to provide information and resources that empower its users and allow them to take ownership of their condition and to manage their renal diet to the best of their ability. Additionally, the site aims to encourage joyful eating by making cooking as easy and as fun as possible for a population that has been told many foods are off-limits.

The main attraction of the Kidney Community Kitchen is its virtual cookbook. It features a wide variety of delicious, dietitian-reviewed and approved recipes. Users can also submit their personal favourites, and volunteer chefs keep the content fresh by sharing a wide variety of appetizing new creations. The cookbook can be filtered by a number of dietary priorities, such as high protein, or low phosphorus, low potassium, and low sodium choices. Users can also search by meal types like family, international cuisine, and vegan alternatives.

This site is a celebration of food for people living with kidney disease – in addition to kidney-friendly recipes, it includes other handy tools to help users manage their diet. Website contents are available in English and French.
The Meal Planner is a unique feature; it is linked to the Canadian Nutrient File, which allows users to add their own preferred food items or any of the recipes from the Kidney Community Kitchen to create daily or weekly plans. The nutritional analysis, including potassium, phosphorus, and sodium amounts, are automatically calculated. With a free membership account, 52 weeks of plans can be saved and printed.

Site visitors will also find information and resources like Renal Diet FAQs, detailed fact sheets on topics such as *Eating Out on a Kidney Diet, Potassium and Phosphorus and Chronic Kidney Disease*, and more. If users can’t find the answer they are looking for from these resources, they can submit a question to a dedicated team of volunteer dietitians. The Kidney Foundation works to continually update the site with new recipes and information. A dietitians’ blog provides timely content, and the video page shares in-depth webinars, cooking demonstrations and chefs’ tips.

Diet can have a big impact on quality of life, from how well one feels to being able to fully participate in family celebration and holiday meals. The Kidney Foundation of Canada created the Kidney Community Kitchen to help address these challenges and to bring more fun and flavour to patients’ and care providers’ lives.

Visit Kidney Community Kitchen at [www.kidneycommunitykitchen.ca](http://www.kidneycommunitykitchen.ca)
The Guatemalan Foundation For Children With Kidney Diseases (FUNDANIER) assists and prevents chronic kidney diseases (CKD) in a country with high population of poverty.

In 2010 in alliance with Ministry (MOH) and Roosevelt Hospital, the Unit for Nephrology, Hyper-tension, Dialysis and Transplant was founded. This Unit has been recognised for its impact on CKD patients. The paediatric mortality rate has been reduced by 80% through 101 transplants, 35200 haemodialysis treatments, psychological and nutritional assistance.

The service provided by FUNDANIER has filled a void in the public health system. Currently the paediatric nephrology programme has reversed the progress of 8 out of 10 cases attended, trained more than 500 general physicians, and trained 10 paediatric nephrologists and thereby impacting 4200 families.
Key programs and events

1. In-centre haemodialysis (subsidized program)
2. Home Nocturnal haemodialysis (subsidized program)
3. Free loan of Automated Peritoneal Dialysis machines
4. Co-Fund Co-use Automated Peritoneal Dialysis machine program
5. Partial sponsorship of drugs for transplant patients and erythropoietin
6. Fundraising for the subsidized programs (US$1.3 million raised during 2021)
Hong Kong Kidney Foundation
Annual Report 2021

7. Memorial garden and plaque to honour the deceased organ donors
8. HKKF Fellowship and Scholarship
9. Renal nursing course
10. Renal research grant
11. Webinars on Better care for patients with diabetes and kidney disease
12. World Kidney Day 2021

Hong Kong Kidney Foundation – Annual Report 2021
https://www.dropbox.com/s/4e27u2maubq7u5/Connect_2107_HKKF%20Annual%20Report%202021.pdf?dl=0
In order to provide holistic care, we have organized whole-week long, intensive multidisciplinary education and lifestyle camps for stage III-V CKD patients and their accompanying closest relatives.

The camps have been organized and led by Kálmán Polner MD, St Margit Hospital, Budapest.

We experienced that our multidisciplinary education with strong psychosocial care resulted in slowing down the progression of renal failure. Patients chose home-based dialysis modality more often and their transplantation activity enhanced significantly. Educating patients together with their close relatives intensified family’s togetherness, increased the relatives’ sympathetic and supportive behavior, and helped the families coping with the disease. The whole week long camp facilitated the development of trustful and empathic relationship among patients, relatives and the educational team members. The whole week long camp facilitated the development of trustful and empathic relationship among patients, relatives and the educational team members.
An article summarizing the results of our multidisciplinary education has been published recently: Kálmán Polner, Erika Sallay, Katalin Detrich, Ágnes Haris: Multidisciplinary education and lifestyle camps for CKD patients and their closest family members: effects on disease progression, self-management and psychosocial condition—a retrospective cohort study. International Urology and Nephrology.

https://doi.org/10.1007/s11255-021-02948-x
Kidney Foundation Kerala, India

Organ donation: opt-in or opt-out system better?

Around the world, organ donation policies vary greatly. Is it best to have a donation system where people have to opt in or opt out?

In India, a new patient is added to the waiting list for an organ transplant every 10 minutes. With an opt-in system, people have to actively sign up to a register to donate their organs after death. In opt-out systems, organ donation will occur automatically unless a specific request is made before death for organs not to be taken.

“People may not act for numerous reasons, including loss aversion, effort, and believing that the policy makers have made the ‘right’ decision and one that they believe in.”

However, inaction in an opt-in system can lead to individuals who would want to be a donor not donating (a false negative). In contrast, inaction in an opt-out system can potentially lead to an individual that does not want to donate becoming a donor (a false positive).
Organ donation: opt-in or opt-out system better?

Many countries currently uses an opt-out system.

We are trying our level best to propagate this message to the decision makers in India and make the society aware of the merit of "Opt out" policy.

Thank you for joining hands to achieve such a great target through spreading awareness of this type of cadaver donation, in a legalised way, in a country like India where patients die who wait for organ, whose approximate death rate is Half a Million per year....!!!!!!

It's our dream to get it implemented in India too. Hope and pray for that....

V. G. Chandrasekharan
Founder &, Chairman
Kidney Foundation Kerala

www.kidneyfoundationkerala.org
Transplant Recipients of India and Organ failure patients – a Movement to Provide Hope
(A Patient Support Group powered by MOHAN Foundation)

**MISSION:** To transform the quality of life of organ failure patients, transplant recipients and caregivers through education, support, awareness and advocacy

**UNIQUE INITIATIVE:** A multi-organ Patient Support group ‘By the Patients, For the Patients, Of the Patients’. Through its city-wise network of chapters, TRIOMPH strives to serve its members and be a well-known and well-respected voice of the community, thereby representing their needs and challenges.

**OUR ACTIVITIES:**

**A. EDUCATION**

- How to take care of your kidneys and prevent kidney failure – with Dr. Rajasekar Chakravarti
- Managing anxiety and isolation during COVID-19 lockdown with Dr. Amol Tayade
- Peritoneal Dialysis & its relevance during COVID-19 with Dr. Georgi Abraham
- How to take care of your Liver with Dr. A.S. Soin and Dr. Sanjiv Saigal
- Concepts of Organ Donation with experts of MOHAN Foundation

**WEBINARS BY INVITED EXPERTS**

**Commemorating WORLD KIDNEY DAY**

- Motivational talk by Dr. Venkat Sumantran – a Living Donor (in association with IFKF & TANKER Foundation)
- Navigating the journey of a CKD patient
PATIENT EDUCATION & SUPPORT WORKSHOPS

‘KIDNEY TRANSPLANT – A GIFT OF LIFE’ WORKSHOPS for Dialysis patients & caregivers

Dialysis patients and their caregivers tend to have apprehensions and misbeliefs about organ donation and transplantation, due to which they may hesitate or even refuse a kidney transplant. More often, lack of knowledge about the processes act as a deterrent. However, kidney transplants offer a much better quality of life to such patients. The objective of TRIOMPH’s workshops is to educate and motivate the patients and their caregivers to know the facts about kidney transplants and decide for themselves.

These workshops are conducted by MOHAN Foundation’s expert Transplant Coordinators in local languages and includes interactions with kidney recipients and living kidney donor.

B. SUPPORT

Helping transplant recipients, persons on dialysis and caregivers become self-reliant and meet their livelihood needs.

Objectives:
- Sensitizing employers about the special needs of this community and putting together a talent pool for enabling gainful employment
- Working with employers under ‘Diversity and Inclusion at Workplace’ for gainfully employing persons from this community, basis merit and requirement.

SPECIAL DISCOUNTED LAB TESTS
(25 - 35%)

TRIOMPH has partnered with a diagnostics aggregator, to provide specially discounted lab tests to its members and their families, thereby alleviating their financial burden.

ANUDAAN – MAKING TRANSPLANTS AFFORDABLE

It is encouraging that organ donations are increasingly saving lives across India. These acts of solidarity and generosity are something to celebrate. However, there is a spoiler in this inspiring tale. Organ transplants are prohibitively expensive.

A huge number of organ failure patients are not benefitting from this life-saving advancement as they are ill-equipped to bear the financial burden of a transplant and therefore give up.

Anudaan provides financial help to the economically poor so they too can have equal access this life-saving procedure.

TRIOMPH
triumph.org.in

12. Mohan Foundation
India
12. Mohan
Foundation
India

C. AWARENESS

MARATHON IN SUPPORT OF ORGAN DONATION

Who better than organ recipients to champion the cause of organ donation!
A few members of TRIOMPH ran the 5 KM DREAM RUN at Tata Mumbai Marathon, with their families and doctors, in support of organ donation.

Their message to the world was loud and clear - “Organ donation and transplantation saved our lives. You too can save lives. Pledge your organs and Support organ donation”

#GetFitwithTRIOMPH

This unique initiative is aimed at raising awareness about the importance of fitness amongst transplant recipients and motivating them to make fitness a way of life. Immunosuppressants and steroids make recipients vulnerable to diseases such as diabetes, high cholesterol, blood pressure and such others.

TRIOMPH invited a few transplant recipients to share tips on their own fitness regimen.

VLOGS by TRIOMPH

TRIOMPH has been uploading Series of ‘Awareness and Patient Education Vlogs’ on important topics such as –

• Taking care of your AV Fistula – a patient perspective
• Diet and Hemodialysis

D. ADVOCACY

TRIOMPH has initiated discussions with Health Insurance companies for providing Health Cover to Live donors and Transplant Recipients. Presently, health insurance is not available to this category of public.
TANKER TURNS 28

June 2021 was a momentous month for TANKER (Tamilnad Kidney Research) Foundation as it marked the completion of the 28th year of its service. June 30 was not just a day to celebrate an anniversary but also to appreciate the selfless work being done by the staff in the dialysis units – we call them Angels on Earth – and re-dedicate ourselves to our mission of helping the underprivileged with kidney ailments.

GOING BEYOND BORDERS

A dialysis unit with 6 machines and other equipment was inaugurated at Pillar Hospital, Port Blair, the capital of Andaman and Nicobar Islands, June 20. Rotary Club of Guindy, its overseas partners and Rotary Club of Port Blair along with TANKER Foundation and Pillar Hospital have set up the Rotary TANKER Dialysis Centre at Port Blair.

STAYING CONNECTED

Toyota Connected India Pvt Ltd handed over 10,000 numbers of 3-ply masks to TANKER Foundation in July. With the pandemic raging, we are grateful for the thoughtful donation which will go a long way in providing protection.
Tamilnad Kidney Research Foundation

PRECIOUS CARGO

TANKER Foundation saw some valuable donations during the harsh second wave of the Corona pandemic in May. Rotary Club of Chennai Towers donated 250 N95 masks to the Foundation, while Muthamizh Sangam of Central Florida, USA, reached across to TANKER in Chennai with two oxygen concentrators and 20 pulse oximeters. Rotary Club of Madras Industrial City chipped in with a generous donation of 100 PPE kits – the protective armour.

HANDSOME OFFER

Dr. Anisha Ashok and Dr. Jayanth Vijayakumar of Laser and Laparoscopic Hospital, Chennai, have offered to do fistula surgeries for TANKER Foundation kidney patients – for free. The hospital only collects miscellaneous charges for consumables.

STAYING CONNECTED

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Tamilnad Kidney Research Foundation

OXYGEN CONCENTRATORS RECEIVED FROM MUTHAMIZH SANGAM, FLORIDA, USA.

INAUGURATION OF DIALYSIS UNIT AT PILLAR HOSPITAL, PORT BLAIR ON 20TH JUNE 2021.

https://www.tankerfoundation.org
Survey About Water Intake Habits Concluded With Intriguing Outcomes

Serving community on kidney health for more than 35 years, Turkish Kidney Foundation, completed a brand new study about nation’s water intake habits. The study was carried out at official social media account of the foundation.

“Inquiries Out Of Water” project aimed to raise awareness of society regarding water consumption for kidney and general health. Outcomes of the survey are surprising.

The survey had conducted between July 22- Sptember 22,2020 at Instagram stories feature and target group age range is specified as from 18 to 65.

The results of the survey, in which more than 850,000 people participated in total, revealed striking details:

• Every one person out of 3 does not know how much water to drink daily!
• Almost 1 person out of 2 does not care amount of daily water intake!
• People who start their day by drinking water in the morning are in majority!
Survey About Water Intake Habits Concluded With Intriguing Outcomes

Other survey questions were:

- Does aromatizing water increase water intake?
- Do you meet your water needs with water or with other beverages?
- Do you know that other cold and hot drinks you drink do not meet your body’s need for water, instead they increase thirst?
- Do you forget to drink water during the day?
- We don’t like to carry water bottle!
- Water consumption decreases out of home!
- Taste, warmth and source of water also count!
- Is the source of the water you drink important to you?
- Are we conscious about the relationship between water and health?
- I know the harms of consuming less water on our body.

[Link to the full report]
15. Forthcoming events

Renal Nutrition, diet and World Kidney Recipes

Focus group (online) meeting for healthcare professionals and patient groups

Webinar for healthcare professionals

To be announced soon