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

IFKF-WKA Connect
4 October 2021
Official Newsletter of IFKF-WKA
Content
1. President’s message
2. Secretary’s Report

Sharing by members
1. Fundanier – Guatemala
2. Hong Kong Kidney Foundation
3. Kidney Foundation Bangladesh
4. The Kidney Warriors, India.
5. Turkish Kidney Foundation, Turkey.
6. Mohan Foundation
7. Tamilnad Kidney Research Foundation
8. FIR – Italy.
9. Forthcoming Events
Welcome to the fourth issue of the IFKF-WKA newsletter (October 2021). I trust this message finds all of you well, as we find our way to co-live with COVID, be it in different ways, with a somewhat different outcome.

We welcome Bangalore Kindy Foundation and Barbados Kidney Foundation as our new members. We look forward to working with and supporting organizations from different parts of the world, especially organizations of smaller sizes.

Kam Kalantar has put in a tremendous effort working with the National Kidney Foundation of Hawaii to set up the Consensus meeting on “Living Well with Kidney Disease”. The hybrid conference (in person or virtual) is a 6-hours event with 21 international speakers from different backgrounds, including patients. The consensus will cover important topics including effective symptom management, improve quality of life, preservative management, home therapies, empowering patients and Care-Partner.

IFKF-WKA members are welcome to join the meeting online. The registration fee is US$100. IFKF-WKA members can apply for waiver of up to 2 registration fees (which will be covered by the Education grant of IFKF-WKA). Please see the information posted at the end of this IFKF-WKA Connect.
SECRETARY’S REPORT
Ms Latha A. Kumaraswami
Secretary & Treasurer, IFKF-WKA

1. We have established a single Official Mail Id to be used for the Secretariat: info@ifkf.org

2. TANKER Foundation & MOHAN Foundation in partnership with IFKF-WKA held two Patient Education & Support workshops for all TANKER patients.

3. Two new members have joined IFKF-WKA (Bangalore Kidney Foundation and Barbados Kidney Foundation. We are grateful to our President for donating the seeding fund for the IFKF-WKA Membership Support Fund (US$ 5000/-) - to support the membership fee for the lower-income countries.

4. An online webinar on Hypertension will be held on 8 December 2021 (see forthcoming event).
On July 5th we resumed our Kidney Transplant Program with our patient Fredy and his mom who was the donor. Through -FUNDANIER- we were able to procure paving stones necessary to cover the parking space which is also used as a pedestrian path by our patients as they enter the unit. Our medical personnel participated in the “Neonatal Nephrology Class”. We also organized COVID-19 vaccination for our pediatric nephrology patients. Certifications of the course “Vivir Intencionalmente” (Living Intentionally by John Maxwell) were given to participants of our unit.
Urodynamics course initiated on August 5th for our medical team. Katie Chandler, from Bridge of Life visited us and gave out some materials and presents to our patients. We received a donation of computers and a server for the implementation of our electronic patient files. We received more equipment donations for our outpatient clinics.

On August 2nd our patient Luis Diego Orellana received his kidney transplant.
On September 1st and 2nd we had our VI Nutrition and Renal Disease Congress virtually. We had local and international participants. We had several activities with our patients to commemorate and celebrate 200 years of our Independence. We had a Civic Act as part of our Independence celebrations.

www.fundanier.org.gt
Hong Kong Kidney Foundation

A Co-Fund Co-Use program Automated Peritoneal Dialysis (APD) program - for a patient to perform peritoneal dialysis overnight at home.

76% of the Hong Kong patients on dialysis are on home dialysis, of which 74% are on CAPD, and only 21% are on APD. The low utilisation of APD is due to the cost of the APD machine (around US$10,000).

Since 1997, Hong Kong Kidney Foundation (HKKF) has supported patients to opt for APD - with the free-loaning of an APD machine. Over the years, HKKF has procured 900 APD machines for the program, amounting to US$7.8 million worth of machine. It is a heavy burden on the fundraising of HKKF. The demand for APD machines cannot be met. Some patients rent an APD machine from the supplier.

On 1 January 2020, HKKF launched the Co-Fund Co-Use (CFCU) APD program. How does this work?

The CFCU program was made possible with the donation of 60 APD machines by two donors and a matching donation of machines by Baxter Healthcare Ltd, created a pool of 90 APD machines for loaning to patient.
A patient joining the CFCU program is to contribute US$300/month to the “CFCU Fund” to use an APD machine at home. His contribution to the CFCU Fund is for a maximum duration of 36 months only. After that, he can use of the APD machine till no longer the need to do so (usually for 4-5 years). The APD machine will then be given to another patient to use (as the machine can function well for 10+ years).

The contribution by a patient for 36 months would have accumulated US$10,000, enabling HKKF to procure another APD machine for another patient to join the program, who in turn, will contribute funding to procure more machines.

Thus, the CFCU program is a self-sustainable program to help the patients, with patients joining a co-funding project and co-use of APD machine.

So far, HKKF has accepted 70 patients for the CFCU program. Their monthly contribution to the CFCU Fund has already accumulated US$250,000 for HKKF. This will enable HKKF to procure more APD machines when the current quota of machines are used up.
Activities of Kidney Foundation of Bangladesh and its branches for last three months from July, August and September, 2021 and in Academic activities, delete 1st one.

<table>
<thead>
<tr>
<th>Hospital Activities (Last 3 Months)</th>
<th>Kidney Foundation &amp; Research Institute, Dhaka</th>
<th>Kidney Foundation Pabna</th>
<th>Kidney Foundation Sirajganji</th>
<th>Kidney Foundation Sylhet</th>
</tr>
</thead>
<tbody>
<tr>
<td>No of HD patients</td>
<td>530</td>
<td>266</td>
<td>57</td>
<td>309</td>
</tr>
<tr>
<td>No of new patients in HD</td>
<td>175</td>
<td>28</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>No of CAPD</td>
<td>7</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>No of Renal Transplant</td>
<td>7</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>No of A-V Fistula performed</td>
<td>366</td>
<td>3</td>
<td>-</td>
<td>5</td>
</tr>
<tr>
<td>No of JVP acute dialysis</td>
<td>363</td>
<td>2</td>
<td>-</td>
<td>10</td>
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<tr>
<td>No of OPD patients</td>
<td>10901</td>
<td>978</td>
<td>-</td>
<td>94</td>
</tr>
<tr>
<td>No of lab services provided</td>
<td>101749</td>
<td>1709</td>
<td>-</td>
<td>695</td>
</tr>
<tr>
<td>No of free dialysis</td>
<td>132</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

**Academic activities**

- Conducting training programme to Renal, nurses and dietitians
- Seminar on live & deceased donor organ transplantation to be held on 21st & 22nd October Bangladesh & Korea University Anam Hospital, Korea
- Weekly case presentation and discussion Director Hospital 16 October 2021
# Bangladesh-Korea Transplantation Webinar-2021

**Date:** 22nd October (Friday)  
**Time:** 4 PM (Dhaka), 7 PM (Seoul)

<table>
<thead>
<tr>
<th>Time (Dhaka)</th>
<th>Agenda</th>
<th>Presenter</th>
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</thead>
</table>
| 4 pm         | Opening Remarks | Dr. Harun Ur Rashid  
Dr. Samuel Lee, CEO of Vitalink |
| **Session 1** | Time: 4:05-4:25 pm (Dhaka time)  
Chairman: Prof. Moon, In Sung  
Prof. Muhammad Rafiqul Alam  
Prof. Muhammad Mamon Mustafii |
| 4:05 – 4:25 pm | Recent perspective in KT in the COVID-19 Pandemic era | Dr. Yong Jaseok (Yonsei Univ.) |
| 4:25 – 4:45 pm | Donation improvement program in Korea (KODA) | 
| **Session 2** | Time: 4:45 – 5:25 (Dhaka Time)  
Chair person: Prof. Khorsshedul Alam  
Prof. Habibur Rahman Dalal  
Prof. Mijanur Rahman (NIKDU) |
| 4:45 – 5:05 | Evaluation and management of brain death donor | Dr. LeeJae Myeong (Korea Univ.) |
| 5:05 – 5:25 | Current status of DDKT in Bangladesh | Dr. Harun Ur Rashid |
| **Session 3** | Time: 5:25 pm – 6:05 pm (Dhaka time)  
Chairman: Prof.Ahm. Curie  
Prof. M. Mulhibur Rahman  
Prof. Kazi Shiyam Alom |

**Kidney Friendly Recipes - Bangladeshi**

- By Kidney Foundation Hospital and Research Institute, Bangladesh

Tazreen Mallick  
Clinical Dietitian  
Member British Dietetic Association

Professor Harun Ur Rashid  
Chairman, Chief Consultant in Nephrology,  
FRC, FCP, FRCP

Dr. Tasnuva Sarah Kashem  
Assistant Professor  
Nephrology

Note: Recipes are meant as guidance only. Patients should seek consultation with a dietician for specific requirements.
Our initiatives since July 2021

July- August: Paediatric kidney disease
- Funding for kids with acute kidney injury (AKI) introduced. Our help reached a kid in Mumbai and one in Kolkata.
- Dr Rajiv Sinha presented Kids with Kidney Disease to our adult patient Group. [https://www.youtube.com/watch?v=tooZjXMomGs&t=406s](https://www.youtube.com/watch?v=tooZjXMomGs&t=406s)
- Dr Uma Ali presented on Kids Kidney, Keep them Safe and Treat them Well. Parents joined to discuss issues.

August: Awareness for Prevention:
Dr Shailesh Kakode presented on “Preventive Measures & Management” [https://www.youtube.com/watch?v=6ez8TYFfSnI&t=1234s](https://www.youtube.com/watch?v=6ez8TYFfSnI&t=1234s)

Panel Discussion on 3rd Vaccination: with Dr Sundar Sankaran, Dr Sanjeev Gulati and Narayan Prasad [https://www.youtube.com/watch?v=mdTVB1cMfQw&t=421s](https://www.youtube.com/watch?v=mdTVB1cMfQw&t=421s)

Panel Discussion on need for Change in Organ Donation Rules: Dr Sanjeev Gulati, Dr Vasanthi Ramesh (NOTTO), Dr Konkana Gurudev [https://www.youtube.com/watch?v=yrE1--qvqM4](https://www.youtube.com/watch?v=yrE1--qvqM4)

August: Post Transplant- Dr Shrinivas Ambike talked about Post Transplant Tests and Medications, responded to patients’ queries. [https://www.youtube.com/watch?v=7eDWnoAGREM&t=670s](https://www.youtube.com/watch?v=7eDWnoAGREM&t=670s)
September: Dialysis
HD vs PD: Dr Rammohan Bhat presented and responded to questions.
https://www.youtube.com/watch?v=olq5a6DjqVU&t=912s
https://www.youtube.com/watch?v=ckCs7AhCiY&t=1s

Upcoming series for Hemodialysis:
- Kidney disease affect the heart - Investigations for dialysis -
- Symptoms and Solutions to Dialysis – Dialysis Access

Nutrition Aspects:
- Our book, Nutritional Secrets has been published in English and Hindi.
  - https://www.amazon.in/dp/1636697208?&tag=notionpcom-21&fbclid=IwAR2GWT2vSIk7UPcFmmEy89vTbHqeuMAqJxZpjZtMaqj6WELJ9Njwtihzh74
- Nutritional Secrets in Tamil, Telugu, Kannada, Malayalam, Bengali, Marathi and Gujarati will soon be available on-line.


Our 4th Anniversary celebrations will be in December 2021
Health Project of Turkish Kidney Foundation

Reaches Out to 60-72 Month Old Kindergarten Kids: Eat Right, Stay Healthy

Turkish Kidney Foundation’s a-decade long project on kidney health, nutrition and better lifestyle education is re-designed to suit for 60-72 month old kindergarten children in order to have them become aware of the connection between these three prominent subjects.

The idea first came out from Governor of City of Kirklareli, located in the Thrace area of Turkey. The governor had complained about his daughter’s choices of junk food and suggested us to start the education from kindergarten level. Considering that what children learn at their earlier life becomes their habit and forms their character, the idea was well adopted by our foundation and we have started to work on it by forming a committee that includes specialists on education, drama and project management.

Committe work has lasted about two years and even during pandemic restrictions, the meetings were held thanks to Zoom. Education specialist member of committee informed us that the education techniques for selected age group should be considered different from ongoing groups which are between ages 9 to 16. We have been trained that those children from 60 months to 72 months can focus on what they are working on for only 25-30 minutes and the session must include dance (movement), music, story telling, Q-A, drama and games.
First, a name is given to the project: **Eat Right, Stay Healthy**. Then, an original story book was written with two different stories. First story is about kidney twins who are searching for “School Food Logo”, a logo which is to be used at school cafeterias to imply safe food for students nationwide. The target is to teach the logo, and expectation is to make children ask for the logo during their purchase at school cafeterias and outside the school. Following the story, each kid gets to be “Sherlock Holmes” by wearing a spectacles (glass parts are removed), a hat and a cape, holding a magnifier to find the hidden school food logo. After finding the logo, kid is rewarded by an achievement ribbon. Children can also play with a tangram, a triangle and square shaped puzzle-like board which is designed to display school food logo.

Second story is about a little girl who likes to eat junk food. One night in her dream, all her internal organs visit her and complaint about their problems due to her food choices. The target of this story is to teach children difference between “healthy food” and “unhealthy food”. After reading the story, children are assigned to place 16 food cards composed by both healthy and unhealthy foods on two different boards according to their healthy and unhealthy status. Red and green signs can also be used according to choice of children.
For the dancing and singing part, an original piece of music is composed. The name of the song is “Grandpa Kidney”, a fictional character inspired from TKF’s president Timur Erk. There is also a dialogue between teacher, Grandpa Kidney and children.

As an instruction manual, a video shooting is used in an USB. This USB eases the teacher’s work. After a 15 minute watch, teachers can be ready to use the whole set. USB also includes music and dialogue voice files, letters to be shared with family, written manuals for teachers in case they need more details.

All of the materials including USB, game cards, costumes, book, signs, tangram, sample letters, ribbons are placed in the box set.

Box sets are approved by the Ministry of Education.

Shipping is provided by Turkish Kidney Foundation to all kindergartens nationwide.
Patient Education workshops for dialysis patients on ‘Kidney Transplant - A Gift of Life’
Conducted in Tamil, in partnership with TANKER Foundation and IFKF-WKA

August 18, 2021 in TAMIL
Ms. Sujatha Suriyamoorthy, MOHAN Foundation

September 21, 2021 in TAMIL
By Ms. Ishwarya Thiagarajan, MOHAN Foundation


This workshops were organised in association with TANKER Foundation and International Federation of Kidney Foundations – World Kidney Alliance (IFKF - WKA), for empowering the dialysis patients and encouraging them and their caregivers to consider a kidney transplant.
The workshops educated the patients about:
- the process of kidney transplant,
- options – living and deceased donor,
- Unmatched living donor
- legal aspects and procedures,
- who can be a living donor,
- registering on the deceased donor waiting list,
- Availing financial help for the needy
- What to expect and keeping oneself positive and in good health while waiting
- Life after transplant – a glance

At the end of these workshops, recipients who received a kidney from deceased donor as well as a living donor, and living donor were invited to share their experiences and testimonials on quality of life after their transplant / kidney donation. Thereafter, the platform was open for the patients, caregivers and the centre’s dialysis technicians to interact and ask questions to the expert / donor / recipient.

More than 100 dialysis patients, caregivers & dialysis technicians of TANKER Foundation attended the programme.

We thank SBI Foundation and SBI Card for their support.

MOHAN Foundation and TRIOMPH thank Mrs Latha Kumaraswami, Mrs Kausalya, TANKER Foundation and IFKF-WKA for their partnership.

Ms. Latha Kumaraswami motivating the patients to attend the workshop in large numbers
Patient Education workshops for dialysis patients on
'Kidney Transplant - A Gift of Life'
In partnership with Nephroplus Dialysis Centres

August 5, 2021 in HINDI
By Ms. Pallavi Kumar, MOHAN Foundation

August 7, 2021 in HINDI
By Dr. Muneet Kaur Sahi, MOHAN Foundation

September 14, 2021 in TAMIL
By Ms. Sujatha Suriyamoorthy, MOHAN Foundation

September 25, 2021 in TAMIL
By Ms. Ishwarya Thiagarajan, MOHAN Foundation
Patient Education: Awareness through Social Media Posts ‘Care For your Kidneys Series’

**FACT #1**
Women are less susceptible to UTI than men.

**TIP**
- Drink plenty of water.
- Avoid holding back urination.
- Maintain personal hygiene.
- Empty the bladder every 2 hours.

**FACT #2**
Renal GPs lead the heart of care.

**TIP**
- Avoid dairy products.
- Avoid meat.
- Avoid processed foods.

**FACT #2**
Do you know DASH?
- Dietary Approach to Stop Hypertension.

**TIP**
- Decrease salt intake.
- Increase fruit, vegetables, and whole grains.

**FACT #3**
Prevent diabetes, prevent kidney diseases.

**TIP**
- Exercise regularly.
- Maintain healthy weight.
- Avoid smoking.

**FACT #4**
Treating UTI: Prevention is the key.

**TIP**
- Sanitize your hands before and after bladder emptying.
- Avoid sharing personal hygiene items.

**FACT #5**
Hypertension & Kidney Disease.

**TIP**
- Manage blood pressure.
- Monitor kidney function.
- Follow a healthy lifestyle.

**FACT #6**
Urinary Tract Infections (UTI) and Kidney Diseases.

**TIP**
- Seek medical advice if symptoms persist.
- Stay hydrated.
- Avoid certain medications.

Webinars by Invited Experts

Mohan Foundation
MOHAN Foundation and its Patient support Group TRIOMPH invited by IFKF-WKA to share patient perspective on “Healthy Food for Healthy Kidney”

On August 20, 2021, IFKF-WKA (International Federation of Kidney Foundations - World Kidney Alliance) conducted a webinar on “Healthy Food for healthy Kidney”, wherein they invited Ms Jaya Jairam to share Patient perspective as a kidney patient and transplant recipient. This session was conducted as part of raising awareness about consuming healthy and kidney-friendly food.
CELEBRATION TIME

August 2021 saw three anniversaries: Tiruppur dialysis unit entered its second year, the Vellore unit celebrated its fourth anniversary and the Retteri unit completed three years. The donors and staff pulled out all stops and had gala celebrations.

BEYOND BORDERS

Dr. Lawrence G. McAlpine, a well-known physician from Glasgow, England, wrote about the great service being rendered by TANKER Foundation Founder-Trustee, Dr. Georgi Abraham, and sent a handsome donation to TANKER.

PAT ON THE BACK

The Rekha Memorial Renny Abraham Ambattur Rotary TANKER Foundation Dialysis Unit was selected by the Government of Tamil Nadu for award of a Certificate of Appreciation ‘for exemplary performance under Chief Minister’s Comprehensive Health Insurance Scheme, in August.
SAD NOTE

The saddest time in August was when TANKER Foundation Managing-Trustee, Mrs. Latha A. Kumaraswami, lost her mother, Mrs. Meena Venkateswaran. That Mrs. Meena Venkateswaran was fondly known as Mother of TANKER speaks volumes about involvement with the Foundation.

ANOTHER COVETED AWARD

TANKER Foundation Founder-Trustee, Dr Georgi Abraham, was presented the CME Excellence Dronacharya Award for ‘Exceptional CME efforts in Nephrology’. Dr Georgi Abraham was among the distinguished doctors and professors of the medical fraternity who were honoured with the Omnicuris CME Excellence Awards 2021.

ONBOARD

TANKER got two new Advisory Members: Ms. Nikhila Sridhar and Ms. Saraswathy Sadasivan. They are TANKER donors and have now come joined as Advisory Members.

WELL-RECEIVED

Mr. N. Ramachandran, a Mylaporean from Chennai, made a generous donation of Rs. 5 lakhs to buy a dialysis machine and the aunt of Advisory Member, Mr. K.V. Balachandar, Mrs. Janaki Krishnan, donated Rs 2 lakhs to the Foundation in September.
Numero Verde gratuito:
Activation of a free telephone number of social utility to which patients can ask questions to experts in order to clarify their doubts (+39 800 822 515).

MyFIR App:
Activation of a free mobile app (Android and Apple available) in which patients can:
- Check their kidneys health.
- Insert their food diary
- Insert and monitor their vital signs;
- Memorize the prescribed therapy;
- Download free kidney friendly recipes.

“5x1000” fundraising campaign.
Heart failure and CKD awareness campaign together with AISC endorsed by the Senate of the Italian Republic with a mobile clinic tour crossing Italy;
Forthcoming
Events

Core Discussions:
- Effective Symptom Management to Improve Quality of Life
- Treating Pruritus, Fatigue, Pain, Sleep and Mental Health
- Expanding Preventative Management and Home Therapies
- Empowering Patients and Care Partners

Structural Overview of the Conference:
- 6 sessions, over 6 hours
- 21 presentations, each 8-10 minutes (9 in-person and 12 virtual presenters, all presentations will be live and interactive - no pre-recording)
- 6 Panel Discussions [20 minutes each]
- 2 breaks (10 minutes each)

Registration:  https://forms.office.com/Pages/ResponsePage.aspx?id=nJK7J_lspq0sOJFak0WVVGje6G67zizbDyprby7Ypbaiq5UNIZUSEIDTExyUJCMEdEWTyzR1BaMudlw4u

Each member organisation can register up to 2 members for virtual attendance with the registration fee @$100 being covered by IFKF-WKA Education Fund.

On the registration form, for question 5 please tick “Waive” and for question 6, please enter “Organisation Member of IFFK-WKA”.

Click here to Register.

Supported by an unrestricted grant from Roche Pharma Switzerland.
8 December 2021 &-8 pm IST

“HYPERTENSION
The Silent Killer”

An Informative Panel Discussion
With Leading Nephrologists and Hypertension Specialist from India & UK.

https://us02web.zoom.us/j/85907574275?pwd=ZStkZVJvakJ3UEYvMndnR2pMVDILdz09
Webinar ID: 859 0757 4275