Living well with kidney disease
積極面對腎病 復康豐盛人生

Hong Kong Kidney Foundation
Hong Kong Society of Nephrology
Hong Kong Association of Renal Nurses

Partner: Alliance of Renal Patient Self-help Association
Events:

- **World Kidney Day @ Hong Kong Webinar** – 7 March 2021
- Newspaper full page special article on 4 newspapers – 11 March 2021
- **World Kidney Day ISN & IFKF-WKA Webinar x2** – 11 March 2021
- **Mass Transit Railway (MTR)**
  - 346 Community poster (small) – 7 to 13 March 2021
  - 30 seconds video clip – March 29 2021 for 5 days (TBC)
  - 95 plays per day, spot telecast in any 107 units of 103" Digital Motion in 27 key stations and any 33 units of concourse.
  - 300 large trackside advertising lightbox panel (5 April 2021 TBC)
- **Radio programs**
  - Metro 8 March 2021 (Dr. SF Lui)
  - RTHK 12 March 2021 (Dr. Cheng Yuk Lung), 19 March 2021 (Dr. SF Lui).
Zoom & Facebook Live
Sunday 7 March 2021
World Kidney Day @ Hong Kong Webinar

Face the kidney disease positively.
Enrich life with full rehabilitation
Active participation
Hand in hand together
Self motivate and be strong

Webinar on the patient questionnaire
Sharing by patients
World Kidney Day @ Hong Kong
7 March 2021
Webinar via Zoom and Facebook live
(around 200 attended via Zoom, 200 on Facebook)
Welcome by organisers

Living well with Kidney Disease
Webinar 7 March 2021

Panel discussion
Address by Prof Sophia Chan, JP
Secretary, Food and Health Bureau

Address by Dr. Constance Chan, JP
Director, Department of Health

Address by Dr. Tony Ko
Chief Executive, Hospital Authority
Patient’s story

Discussion by guest panel
Kidney disease -> a burden, a challenge

Troublesome symptoms, Affecting all parts and function of the body mobility, daily live activities, work and way of life Also affecting family members and friends.

Patient

hopes to continue life freely with dignity maintains his/her role and in the function in the society Able to manage and control own health and wellbeing.

Life participation

is important for patient and his carer
Kidney disease management

Current: Disease-centred
renal replacement therapy to prolong life

Future: Patient-centred
Patient’s priority and value, overall effectiveness

Current: Negative, restraint, limitation, oppression

New way: Active, autonomous, participating, possessing

Motivate them to be an active participant in the care process
1. **Empower** patients with CKD and their family members or other care-partners to achieve the health outcomes and life goals that are meaningful and important to them.

2. 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.

3. 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.

4. More effective and more integrated and holistic **symptom management** for all patients with kidney disease beyond traditional kidney therapies.

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**Framework**

"Living well with kidney disease"

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**From framework to ACTION**

**Patient participation Patient-centred**

We must move **beyond the status quo** and advance patient-centeredness in research, practice and policy.

**Patient empowerment, partnership** and improved communications, combined with a paradigm shift towards a **strengths-based approach** to care, can inspire confidence and hope in patients that they can live well with CKD.
A patient survey for an organisation/renal unit to find out

- How patient are doing on “Living well with the kidney disease”?
- What issues are troubling, worrying or preventing them from living well?
- What matters to them most?
- What may they wish others (family members, healthcare professionals & system) could do for them or options that they would like to have to live well?
- What can they do for themselves to live well?

What may be troubling you (physical)?

- Fatigue: 61%
- Sleep disturbance: 47%
- Shortness of breath: 47%
- Headache: 41%
- Fatigue: 36%
- Mobility: 31%
- Thirsty: 28%
- Poor Appetite: 24%
- Swollen legs: 23%

What may be troubling you (psychological)?

- Concern about future: 57%
- Anxiety: 42%
- Stress: 38%
- Concern about rejection (transplant patient): 18%
- Depression: 17%

What may be troubling you (life impact)?

- Concern about the need to start dialysis (pre-RRT):
  - No: 50%
  - Financial matters: 39%
  - Diet: 38%
  - Events: 38%
  - Impact on ability to work: 35%
  - Ability to travel: 35%
  - Social activities: 29%
  - Lifestyle changes: 16%
  - Ability to study: 8%
What may be troubling you?
Top 3 items (physical, psychological, life impact)

- Fatigue: 27%
- Financial matters: 21%
- Concentration: 19%
- Sleep disturbance: 15%
- Mobility: 12%
- Diet: 12%
- Miscellaneous: 12%
- Impact of family and friends: 11%
- Blood restriction: 11%
- Ability to work: 10%
- Travel: 9%
- Smoking: 9%
- Alcohol: 8%

What can you do yourself to live better with kidney disease?

- Take better care of myself: 67%
- Comply with medication: 65%
- Keep fit with exercise: 50%
- Comply with dietary treatment: 46%
- Watch body weight: 44%
- Eat more, eat well: 43%

Theme of 2021

- Understand my disease and treatment: 37%
- Self-care: 37%
- Make plan for the future: 24%
- Taking part in self-care: 13%

How can others (medical system/professionals) assist you to live well with kidney disease?

- Empathy
- Consider from the perspective of the patient
- Listen and communication
- Provide more information
- Actual support +++

How can others (family and friends) assist you to live well with kidney disease?

- Active concern and care
- Encourage, support, understanding
- Listen and communicate
Dr. Lui Siu-Fai
President,
International Federation of Kidney Foundations – World Kidney Alliance

Living well with kidney disease
International Pilot Study of 8 organisations from 7 countries

<table>
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<th>Malaysia</th>
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<th>India Tanker Foundation</th>
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Q3a. Physical

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<tr>
<th>Fatigue 57%</th>
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<td>44%</td>
<td>44%</td>
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<tr>
<td>Weakness</td>
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<td>42%</td>
<td>42%</td>
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<tr>
<td>Pain</td>
<td>30%</td>
<td>30%</td>
<td>30%</td>
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<tr>
<td>Shortness of breath</td>
<td>30%</td>
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<td>30%</td>
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<tr>
<td>Sleep problems</td>
<td>30%</td>
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<tr>
<td>Fatigue</td>
<td>30%</td>
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<tr>
<td>Weakness</td>
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<tr>
<td>Pain</td>
<td>30%</td>
<td>30%</td>
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<tr>
<td>Shortness of breath</td>
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Q3b. Psychologic

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<th>Concern about the future 57%</th>
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<tr>
<td>Depression</td>
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<tr>
<td>Anxiety</td>
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<td>20%</td>
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<tr>
<td>Stress</td>
<td>15%</td>
<td>15%</td>
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<tr>
<td>Depression</td>
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<td>10%</td>
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Q3c. Life Impact

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<td>Ability to travel</td>
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<tr>
<td>Ability to travel</td>
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<tr>
<td>Ability to learn</td>
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<tr>
<td>Impact on family and friends</td>
<td>15%</td>
<td>15%</td>
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<tr>
<td>Impact on family and friends</td>
<td>10%</td>
<td>10%</td>
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Q4. Top 3 concerns/problems

<table>
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<th>Fatigue</th>
<th>Concern about the future</th>
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<tr>
<td>27%</td>
<td>22%</td>
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<table>
<thead>
<tr>
<th>Financial impact</th>
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<tr>
<td>21%</td>
<td>23%</td>
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<table>
<thead>
<tr>
<th>Fatigue</th>
<th>Concern about the future</th>
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<td>45%</td>
<td>43%</td>
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<table>
<thead>
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<th>Lifestyle changes</th>
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<td>24%</td>
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<table>
<thead>
<tr>
<th>Fatigue</th>
<th>Concern about the future</th>
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<td>46%</td>
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<table>
<thead>
<tr>
<th>Fatigue</th>
<th>Concern about the future</th>
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<td>64%</td>
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<table>
<thead>
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<th>Impact on family and friends</th>
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<tr>
<td>63%</td>
<td>65%</td>
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郁一郁、笑一笑、明天會更好。

https://youtu.be/yw0oWFvxgm8

The online dance for World Kidney Day 2021 at Hong Kong by the Hong Kong Kidney Foundation Dance Group
The popular “Crab dance” originated from Thailand, to relieve stress.
(as we have been tied down by COVID for too long).
主支持夥伴
香港安斯泰來製藥有限公司
阿斯利康香港有限公司
德國寶靈家殷格翰(香港)有限公司
費森尤斯醫藥香港有限公司

協和麒麟香港有限公司
瑞士諾華製藥(香港)有限公司
暉致香港
賽諾菲香港有限公司

支持夥伴
百特醫療用品有限公司
費森尤斯卡比香港有限公司
香港大塚製藥有限公司
ISN & IFKF-WKA Webinar: World Kidney Day 2021: Living well with kidney disease

Patient engagement: What matters to patients

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

https://youtu.be/H1QZ0fx0anY
Full page special article on 4 newspapers
Messages from
Ms. Rita Fan, GBS, JP. Patrons of Hong Kong Kidney Foundation
Professor Sophia Chan, JP. Secretary of Food and Health Bureau
Dr. Constance Chan, JP. Director of Health
Mr. Henry Fan, Chairman, Hospital Authority.
Dr. Tony Ko, Chief Executive, Hospital Authority.
Dr. Leong Che-Heong, GBM, GBS, JP. President, HKKF
Professor Richard Yu, SBS. Patron, HKKF

Professor Vivekanand Jha, President, ISN
Dr. Siu-Fai Lui, BBS, MH, JP. President, IFKF-WKA
Professor Philp Li, Convenor, WKD Steering committee
Are your kidneys OK?

Are you at risk of kidney disease?
Do you have diabetes, hypertension past medical or family history of kidney disease?
If you have, you are at risk.

1 in 10 has variable degree of kidney disease

At the early stage of kidney disease, there may not be any symptom

Kidney disease may progress to end-stage kidney failure.
Every year, around 1400 new cases of end-stage kidney failure in Hong Kong, requiring renal replacement therapy (dialysis or kidney transplant) to maintain life.

Kidney disease causes many physical symptoms, also has psychological burden and affecting daily life and living.
World Kidney Day 2021
Living well with kidney disease

The voice of the patient
Result of the patient questionnaire on living well with kidney disease

We (healthcare professionals) care for patients with kidney disease.
Better care. Walk with you together. We will enhance the treatment and rehabilitation.
Active Participation. Be strong.

Photo of healthcare professionals and supporters (Pharmaceutical companies)
腎病治療新理念 鼓勵患者積極參與

調查：70%腎病患者“收緊生活圈”

【香港財經時報】記者張瑞傑報道：今年世界腎臟日的主題為「積極面對腎病：健康優質人生」，香港腎臟基金會、香港腎臟護理學會及香港腎臟護理師學會聯合進行一項調查。成功收錄1,138名現存患者，結果顯示受訪者的治療生活及自我評估平均分數為6.3分，反映腎臟疾病社會影響。再訪患者及隨訪患者的參考率為35%。調查發現，腎友身邊的主要支持包括親友、同事、醫生及施術者。受訪者表示，隨著腎病治療的進展及腎友間的互助，腎友對腎病治療的態度已有所改善，對生死的態度亦有所改觀。調查結果亦顯示，70%腎友均表示「收緊生活圈子」，而70%的腎友表示「收緊生活圈子」。

【調查數據】

香港腎臟基金會、香港腎臟護理學會及香港腎臟護理師學會聯合進行一項調查。成功收錄1,138名現存患者，結果顯示受訪者的治療生活及自我評估平均分數為6.3分，反映腎臟疾病社會影響。再訪患者及隨訪患者的參考率為35%。調查發現，腎友身邊的主要支持包括親友、同事、醫生及施術者。受訪者表示，隨著腎病治療的進展及腎友間的互助，腎友對腎病治療的態度已有所改善，對生死的態度亦有所改觀。調查結果亦顯示，70%腎友均表示「收緊生活圈子」，而70%的腎友表示「收緊生活圈子」。
HKKF Facebook on World Kidney Day
Dr SF Lui on Radio program “Living happily”

Dr YL Cheng on RTHK1
12 March 2021

Dr SF Lui on RTHK1
19 March 2021

[香港腎科學會系列] 主題：腎病風險你要知
嘉賓：鄭玉麟醫生 (香港腎科學會主席)
https://www.rthk.hk/.../episode/737437/autoplay/archive/2

https://www.facebook.com/2268535053209515/posts/3980785365317800/
Mass Transit Railway (MTR)

346 Community poster

7 to 13 March 2021
Mass Transit Railway (MTR) 300 large trackside advertising lightbox panel (5 April 2021 TBC)
Mass Transit Railway (MTR)

30 seconds video clip
March 29 2021 for 5 days (TBC)

95 plays per day, spot telecast in any 107 units of 103" Digital Motion in 27 key stations and any 33 units of concourse.
Follow up action (proposals)

• **Research into key symptoms** (fatigue, sleep problem)
  To be commissioned and funded by Hong Kong Kidney Foundation and Hong Kong Society of Nephrology (to be confirmed)

• **Eat smart, eat well**
  With Hong Kong Society of Nephrology, HK Dietitian Association, Patient group.

• **Patient self-evaluation and reflection tool/ process**
  - To develop an Apps or hard copy for a patient to conduct periodic self review (such as for annual review), to share with healthcare professionals, family/friends.