

16th World Kidney @ Hong Kong

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).















第十六屆世界腎臟日在香港



2021年3月7日星期日 早上十一時至十二時十五分

在線網絡研討會及活動



https://www.facebook.com/hkkf1979

https://cutt.ly/dliiQAT

積極面對腎病 復康豐盛人生 積極參與 携手同行 勉力自強

主題講座、病人問卷調查報告、病人及醫護分享

主禮嘉賓

食物及衞生局局長陳肇始教授 JP 醫院管理局行政總裁高拔陞醫生

香港腎臟基金會會長梁智鴻醫牛 GBM GBS JP





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















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



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



Address by Dr. Tony Ko Chief Executive, Hospital AUthority









積極面對腎病 復康豐盛人生

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.

積極面對腎病 復康豐盛人生

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.

積極面對腎病 復康豐盛人生

Life participation

is important for patient and his carer

11 PP

積極面對腎病 復康豐盛人生

Kidney disease management

Current: **Disease-centred**

renal replacement therapy to prolong life

Future: Patient-centred

Patient's priority and value, overall effectiveness •

積極面對腎病 復康豐盛人生

<u>Current</u>: Negative, restraint, limitation, oppression New way: Active, autonomous, participating, possessing

Motivate them to be an active participant in the care process

積極面對腎病 復康豐盛人生(1)

- 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

Framework "Living well with kidney disease"



advance patient-centeredness in research, practice and policy.

We must move **beyond the status quo** and

積極面對腎病 復康豐盛人生(3)

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.

From framework to <u>ACTION</u>

Patient participation Patient-centred

15 PP

16



積極面對腎病,復康豐盛人生

如何生活得更好?

香港腎臟基金會、香港腎科學會、香港腎科護士學會 聯合與辦

病人問卷調查

- 現時你的生活過得好嗎?
- 那些事項令你的生活過得不好?
- 你可以做些什麼事令你的生活過得好些?
- 醫護人員/家人如何可以在醫療項目、生活或其他方面協助你?

問卷可協助你進行自我評估和反思。

我們想知道您的狀況·可能困擾您的事情 以及我們能為您做些什麼?

2021年1月11日至2021年2月11日 請花**5**分鐘時間填寫在線問卷。 (不記名的、請只填寫一次)



請開啟手機或平版電腦的相機功能· 對準QR碼掃描·即可馬上進行問卷作答 或用這連結 https://cutt.ly/OjteJga

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?

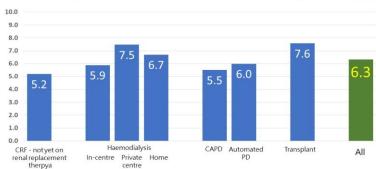
19

Am I living well with kidney disease ? (1-10 分)

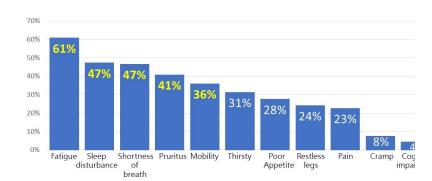
Score

Am I living well with kidney disease ? (1-10 分)

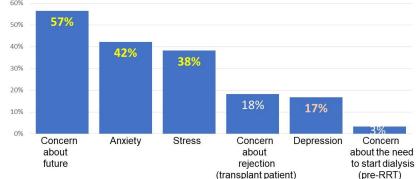
6.3 + 2.0



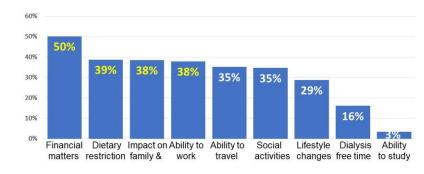
What may be troubling you (physical)?



What may be troubling you (psychological)?

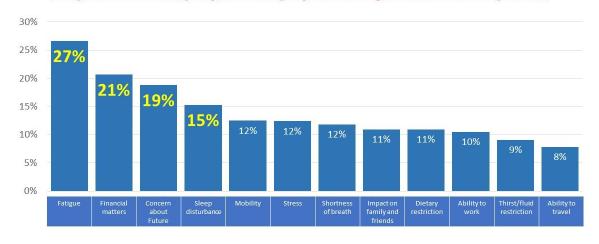


What may be troubling you (life impact)?

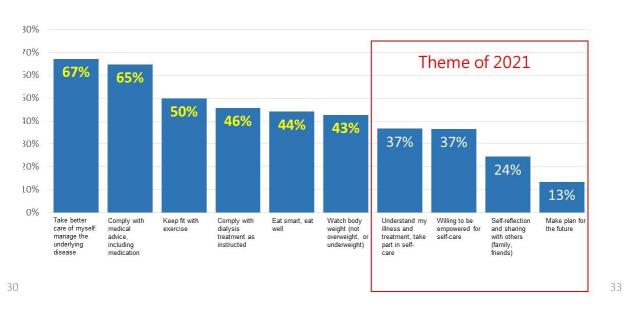


PP PP

What may be troubling you? Top 3 items (physical, psychological, life impact)



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



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

PP 39 PP



Dr. Lui Siu-Fai President, International Federation of Kidney Foundations - World Kidney Alliance



Hong Kong		Malaysia		Bangladesh		India Tanker Foundation		Hungary		Italy	
Q3a. Physica											
Fatigue	61%	Fatigue	57%	Fatigue	59%	Fatigue	55%	Fatique	71%	Fatique	57%
Sleep problems	47%	Cramp	44%	Poor appetite	44%	Thirsty/Fluid restriction	40%	Mobility	46%	Thirsty/Fluid restriction	on 37%
Shortness of breath	47%	Thirsty/Fluid restriction	42%	Sleep problems	38%	Sleep problems	37%	Pruritus (itchiness)	41%	Sleep problems	35%
Pruritus (itchiness)	41%	Sleep problems	40%	Pruritus (itchiness)	36%	Cramp	36%	Sleep problems	41%	Cramp	23%
Mobility	36%	Restless legs	24%	Pain	31%	Shortness of breath	30%	Cramp	32%	Pruritus (itchiness)	22%
Q3b. Psycholo	100	Concern about						Concern about		Concern about	
the future	57%	the future	45%	Anxiety	39%	Anxiety	55%	the future	66%	the future	58%
Anxiety	42%	Stress	27%	Depression	23%	Concern about the future	50%	Anxiety	39%	Anxiety	34%
Stress	38%	Anxiety	19%	Stress	16%	Stress	36%	Stress	31%	Stress	29%
Depression	17%	Depression	9%	Concern about the future	5%	Depression	28%	Depression	17%	Depression	19%
Q3c. Life Imp	act	V-		-							- 10
Financial impact	50%	Financial impact	51%	Financial impact	59%	Financial impact	64%	Lifestyle changes	44%	Lifestyle changes	54%
Diet restriction	39%	Lifestyle changes	48%	Ability to work	40%	Ability to work	47%	Ability to work	40%	Impact on family and friends	41%
Impact on family	38%	Diet restriction	40%	Impact on family	36%	Diet restriction	43%	Financial impact	38%	Ability to travel	39%

Ability to travel

Lifestyle changes

33% Ability to travel

Impact on family

35% Ability to work

33% Diet restriction

Lifestyle changes

31% Social activities.

Ability to work

Social activities.

35% Ability to travel



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

	Hong Kong	Malaysia	Bangladesh	India Tanker Foundation	Hungary	Italy
Number	1138	1255	350	618	256	905
Mean Score	6.3	6.9	5.8	6.7	6.6	6.2
SD	2.0	2.1	2.0	2.5	2.1	2.0

India Tanker Malaysia Hungary **Hong Kong** Italy Bangladesh

Foundation

Q4. Top 3 concerns/problems

Fatigue	27%	Concern about the future	23%	Fatigue	43%	Financial impact	44%	Fatigue	45%	Fatigue 64	%
Financial Impact	21%	Financial Impact	23%	Financial Impact	37%	Concern about the future	31%	Concern about the future	24%	Impact on family and 63' friends	%
Concern about the future	19%	Fatigue	20%	Poor appetite / diet restriction	27%	Anxiety	29%	Mobility	23%	Lifestyle changes 56	%
Sleep problems	15%	Thirsty/ Fluid restriction	15%	Sleep problems	18%	Fatigue	27%	Sleep problems	15%	Concern about 511 the future	%
Stress	12%	Sleep problems	13%	Shortness of breath	14%	Poor appetite / diet restriction	20%	Thirsty/ Fluid restriction	14%	Thirsty/ Fluid restriction	%



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



March 11, 2021 2 sessions: 11 am CET I 10 pm CET





ISN & IFKF-WKA Webinar: World Kidney Day 2021: Living well with kidney disease

Tess Harris - Session 1
President, PKD International.

CEO, Polycystic Kidney Disease Charity,



Vivekanand Jha ISN President. Executive Director,

The George Institute for Global Health,



Siu-Fai Lui President, IFKF - World Kidney Alliance.

Adjunct Professor, JC School of Public Health and Primary Care, The Chinese University of Hong Kong.



Allison Tong
Principal Research Fellow,
Sydney School of Public Health,
The University of Sydney, Australia.



Kamyar Kalantar-Zadeh

Chief, Division of Nephrology, Hypertension and Kidney Transplantation Tenured Professor of Medicine, Pediatrics, University of California Irvine, USA.



Co-Chair, WKD Steering Committee. Senior Consultant Physician and Honorary Professor of Dep. of Medicine and Therapeutics, Prince of Wales Hospital, Chinese University of Hong Kong, China.

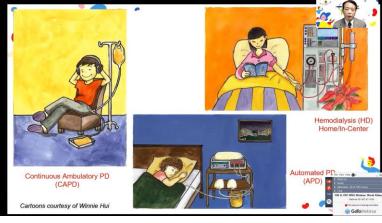


Richard Knight - Session 2

American Association of Kidney Patients,



https://youtu.be/H1QZ0fx0anY











Full page special article on 4 newspapers







第16屆世界腎臟日在香港









享受身心安康



護腎同心



培元養志 行健復康



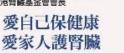
攜手護腎康 積極建新生



健腎同行 愛澤一生



梁智鴻醫生 GBM, GBS, JP





早察覺 勿輕視 重復康 得豐盛



Professor Vivekanand Jha



全球關注腎病 積極預防 腎友積極參與 勉力自強







重探討病人如何加強對治療的參與 更好的自理能力,以及致力跟醫護人員加強溝通為重點

高警覺實刻不容緩。今年大會亦繼續推廣 民關注個人的腎臟健康

積極面對腎病 復康豐盛人生 祝各位康泰平安,生活愉快

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

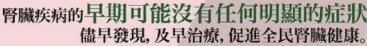
Professor Vivekanand Jha, President, ISN Dr. Siu-Fai Lui, BBS, MH, JP. President, IFKF-WKA Professor Philp Li, Co-convenor, WKD Steering committee 您的腎臟

您有患腎臟疾病的風險嗎?

您是否有糖尿病,高血壓,已往腎病病史,家族腎病病史?

如果是,您可能屬於腎臟疾病的高危人群之一

建康?



香港每年約有1400名病人患上末期腎衰竭,

需要透析治療以維持生命。

腎病患者有生理症狀, 也有心理影響

並影響他們的日常生活。





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.

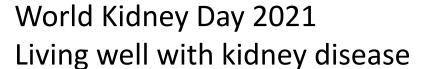
Every year, around 1400 new cases of end-stage kidney failure in Hong Kong, requiring renal replacement therapy (dialysis or kidney transplant) to maintain life.

Kidney disease causes many physical symptoms, also has psychological burden and affecting daily life and living.

2021年世界腎臟日的主題 積極面對腎病 復康豐盛人生 ·







The voice of the patient

Result of the patient questionnaire on living well with kidney disease

(Photo of patient activities)

We (heathcare 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)

Other newspaper reports



逾70%腎病患者拒表達自我 學會籲病人能向別人抒發

分 推介 0 分享



調查發現逾70%腎病病人不願表達自己感受。(受訪者提供)

為響應世界腎臟日,有學會透過調查,進行一項大型末期腎衰竭病人

目前本港有1.3萬名末期腎衰竭病人正接受腎臟替代治療,而每年新 症約有1.300人。事實上,目前每10位市民便約有1位患有不同程度 進行一項調查,成功訪問1138名緊病病人,發現超過70%患者不願 表達自我感受,較少與他人分享自己的病況,亦有逾80%患者沒有計 劃自己的未來路向,反映目前的腎病治療單聚焦在疾病本身,較少照 顧患者的心靈需要。

三個主辦學會認為,國際醫療界正強調慢性疾病應以病人為中心,除 了治病的本身, 亦要顧及患者的自身需要, 讓患者積極投入地面對腎 病, 進一步提升自己的生活質素。

https://hk.on.cc/hk/bkn/cnt/news/20210307/bkn-20210307221809857-0307 00822 001.html

2021-03-08 星期一 www.hkcd.com 財經大報 商界平台



首頁>新聞>香港

調查發現本港6成洗腎病人身心社有困擾

2021-03-07 16:58 來源:香港商報網

香港腎臟基金會、香港腎科學會、香港腎科護士學會主辦「世界腎臟日在 香港」,大會指今年世界腎臟日的主題是「積極面對腎病 復康豐盛人生」 並公布了在年初進行的「如何活得更好些? | 問卷調查結果

此次問卷調查成功收回1138份問卷, 結果顯示受訪者對患者生活之自我 評分平均分為6.3分,反映醫療措施和社會配套,再加上病人提高主動性及 參與才能改善目前狀況。

調查發現,腎友在生理上的主要困擾包括疲勞、睡眠問題和唔夠氣與痕 癢,分別有61%、47%和41%受訪者選擇;心理方面的主要困擾是擔心未來 情况、憂慮和精神壓力,有57%、42%和38%受訪者選擇,至於生活方面的 主要困擾有經濟問題、飲食限制和對家人及朋友的影響、工作能力,各有 50%、39%和38%受訪者選擇。

香港腎臟基金會、香港腎科學會、香港腎科護士學會表示,問卷調查顯示 有67%腎友認為能夠好好照顧自己和控制病情可以令自己生活過得好些、 65%腎友認為遵從醫生建議如用藥可令自己生活過得好些,而50%腎友認為 保持身體健康、多運動可令自己生活過得好些。

大會指國際醫療界現正強調慢性病應以病人為中心作更好的治療和復康基 礎, 而新理念是顧及患者價值觀和整體成效, 至於新模式是講求積極、自 主、投入和擁有,因此醫護應激勵腎友在治療中成為積極參與者,確保他們 之終身性參與,這對腎友及其護理夥伴是同等重要。

香港腎臟基金會、香港腎科學會、香港腎科護十學會透露,香港目前有1 萬3千多名末期腎衰竭病人正接受腎臟替代治療、每年新症約有1300人、而 現時每10位市民中便約有1位患有不同程度的腎病,因此如何加強預防腎病 及如何優化治療末期腎衰竭都是刻不容緩的。

香港商報版權作品,轉載須註明出處。

[責任編輯: 靜文]

腎病治療新理念 鼓勵患者積極參與

【香港商報訊】記者周偉立報道:今年世界腎 。香港腎臟基金會、香港腎科學會、香港腎 科護士學會早前進行一項調查,成功收回1138份 問卷,結果顯示受訪者對患者生活之自我評分平 均分為6.3分,反映醫療措施和社會配套,再加上 病人提高主動性及參與才能改善目前狀況。調查 發現,腎友生理上主要困擾包括疲勞、睡眠問 題、唔夠氣、痕癢等,分別有61%、47%和41%受 訪者選擇;心理方面則擔心未來的情況、憂慮以 及精神壓力,則有57%、42%和38%受訪者選擇。 而生活方面,經濟問題、飲食限制,以及對家人 及朋友的影響和工作能力,各有50%、39%和38% 受訪者選擇。

調查又指,有67%腎友認爲能夠好好照顧自己 和控制病情可以令自己生活過得好些,65%腎友 認爲遵從醫生建議如用藥可令自己生活過得好 些,而50%腎友認爲保持身體健康、多運動可令 自己生活過得好些。而選擇表達個人感受、與他 人交談分享,以及計劃未來安排均屬百分比偏 低,反映目前腎病治療停留於以疾病爲中心,單 以替代治療法去延長壽命。模式屬於消極、拘 東、限制和壓迫的。

他們指,國際醫療界正強調慢性病應以病人爲 角色和社會功能,能夠管理操控個人的健康和福 祉。而新的理念是以病人爲中心、顧及患者價值 觀和整體成效。新模式講求積極、自主、投入和 極的參與者,要確保他們的終身性的參與,這對 於腎友及其護理夥伴是同等重要。



調查:70%腎病患者「收埋自我」

極面對未來的生活。

心靈需要 缺少照顧

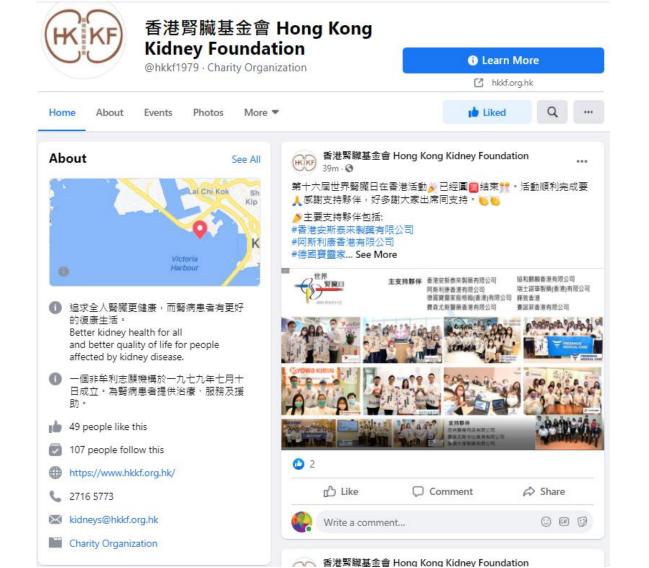
前每10位市民,便約有一位患有不同程度的腎病

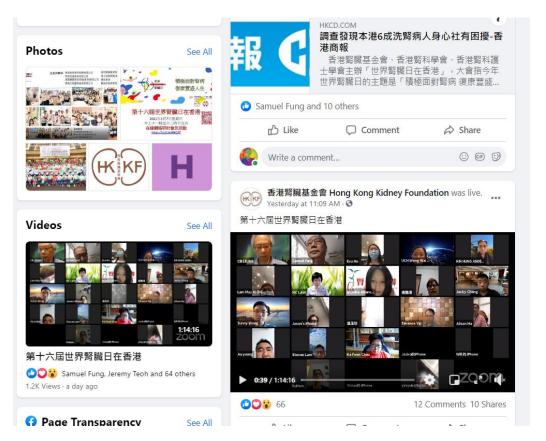


(受訪者提供)

http://www.hkcd.com/content/2021-03/07/content 1253526.html

HKKF Facebook on World Kidney Day





Radio programs 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)

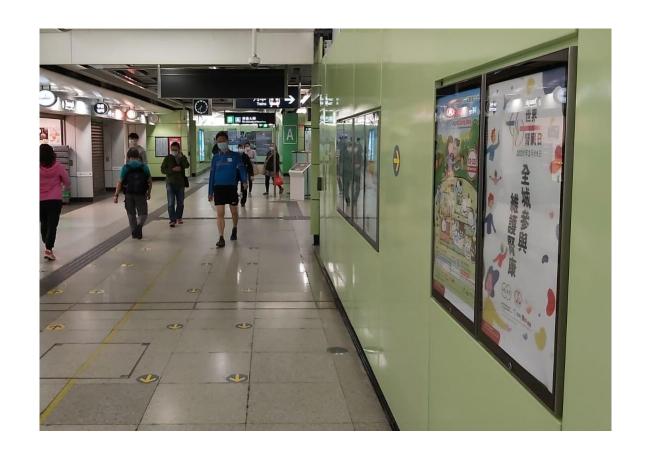
https://www.rthk.hk/.../episode/737437/autoplay/archive/2

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)





香港每年約有1400名病人患上

末期腎衰竭需要透析治療 以維持生命

















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.