

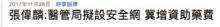
# To generate rare storm among the public bysocial media

Do you know how many patients with rare disease living in **Hong Kong**?

The Secretary for Food and Health might answer:

**11** We have **1**, because we have no definition of rare disease. ""





日上表示,就空見病患者藥费高品, 有藥無錢買的問題,計劃另設「安全 網」・由以往「能者自付」改為「能 者可付」,相信資助額會有所提高。

可以負擔到的就要付費,不能負擔的

則有基金幫助 • 如果做到「能者可 付」,即家境較好的,負擔可能多些,但都是在一個可負擔範圍內,不會令其資產 不斷蒸發,致生活水平急速下降。

張偉麟稱,制訂新資助額時,不會考慮財政問題,因為財政來源不是來自醫管局的 撥軟,而是來自關愛基金。



Written reply by the Secretary for Food and Health, Dr Ko Wing-man, in the Legislative Council on May 6, 2015:

**66** Currently, there is no definition of or comprehensive database on rare diseases in Hong Kong. 77



# **Hong Kong Alliance for Rare Diseases**

Hong Kong Alliance for Rare Diseases (HKARD), established in December 2014, is the first patients' group comprising cross-rare-disease patients and their families with the support of experts and academics. It aims at ensuring respect and protection for patients in terms of such fundamental rights as healthcare, social support, education and daily needs equal to other citizens. We engage the media focusing on the gap between patients' needs and the services delivered by public health in particular access to treatment.

### **Generator of RARE Storm**

We launched the **facebook fan page** in early 2017. We keep on updating by 2-3 times every week with news, stories, features and information by text, photos and audio-visual media.



## Source of the Storm

On 11 April, 2017, a lady with tuberous sclerosis complex (TSC), whooped desperately at a public hearing on rare disease of Legislative Council. She had no money to pay for treatment while Hospital Authority said she is not eligible to be funded. She cried: "I don't want to die... I need treatment...". Twelve days later, she left the world......

HKARD posted a video clip of the lady's verbal submission at the public hearing on facebook after the lady's death, and strongly urged the Government tochange its cold and heartless mind to patients with rare disease! The video was rapidly spreaded over into great number of groups. Most media have shared our video through their facebook pages. Around **1,000,000** views **(1/7 of Hong Kong's population)** and 1458 shared eventually.

The action has successfully generated an unprecedented RARE storm among the press and public by **sparkling a** heat debate over whether more public resources should be input on patients with rare disease to save their life.

# Change by the Storm

Rare Disease becomes common topic for news report, feature, docudrama... of main stream and social media.

# **After the Storm**

Subsequently, we had meetings with the authorities to address specific issues and cases. One notable breakthrough was that the Government has awared and recognized the disabilities in the healthcare system that makes the public health service being not able to respond the needs of access to treatment for at least some patients even the number is small.

The authorities have accepted our recommendation to build up a third level safety net for ultra-expensive orphan drugs which shall set ceiling for cost of treatment paid by patients that must not impact patients and their family's quality of life. A new mechanism by which patients can access high cost treatment with preliminary data on efficacy and for small numbers of patients that looks a new path other than the current enlistment process.

On specific cases, orphan drugs for *Paroxysmal Nocturnal Hemoglobinuria (PNH)*, *Atypical hemolytic uremic syndrome (ahus)*, *Tuberous sclerosis complex (TCS)*, *Mucopolysaccharidosis type 4A(MPS4A)* etc. were provided to patients in need under safety net since summer last year.

# Rare disease is no longer rare on media!

#### Hong Kong Alliance for Rare Diseases

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