



To generate rare storm among the public by social media

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

The Secretary for Food and Health might answer:

“ We have **0**, because we have no definition of rare disease. ”



Credit to on.tv



Credit to hkej.com and TVB News



Credit to RTHK

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

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



香港罕見疾病聯盟
Hong Kong Alliance for Rare Diseases

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.

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 to change 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.

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.



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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