

# Disarray to Distinction: fast track restructuring of hemophilia care in Hong Kong. Abstract 1231 Board 59 9-July-2012

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## OBJECTIVES

Historically, HK hemophilia care is distributed among 9 pediatric units. Since hemophilia is a lifelong condition with many medical needs, patient-group involvement and inter-disciplinary care is essential. Despite being an affluent city with full medical coverage, hemophilia care in Hong Kong (HK) is fragmented. There is lack of pediatric adult transfer plans, treatment protocols, proper communication between hospitals and with the government, and a complete absence of designated hemophilia nurses and physiotherapists.

## METHODS

A review of the restructuring of citywide hemophilia care was commissioned by the government and helped by WFH. Factor usage was used to identify all patients. Cluster pediatrician, physician and patient jointly decide on service needs, modeled on the World Federation of Hemophilia (WFH). The 7-million population of HK is divided into 7 administrative districts. In each district hospital, a hemophilia "local cell" was formed, consisting of 5 members: an adult and a pediatric hematologist, a physiotherapist, a nurse specialist and an ELECTED patient representative. Likewise an elected central "mother cell" of 5 members deals with the government. Service gaps between the local standard versus the WFH standard (developed countries) were identified. The hemophilia campaign was bundled with a mirror thalassemia campaign to increase voice and clout. The extra resources and manpower needs were calculated and put forward to the government at a patient government summit (5-Jun-2010). In a two year staged application process, hurdles were overcome by means of hospital-by-hospital lobbying, media pressure, political party involvement and common-sense talk with the central authorities.

## RESULTS

There are 222 male (192 hemophilia A, 30 hemophilia B, 43% severe, 33% moderate, 24% mild, median age 25.4 years, range 1-76, 27% under age 18). They use 12.8 million units Factor VIII and 3 million units Factor IX annually (1.83 units FVIII per capita). The following objectives were achieved or included into corporate plan: one designated nursing officer appointed per district for hemophilia (plus thalassemia) care; endorsement of "Factor First" policy at casualty; agreement on treatment protocol and transfer age between adult and pediatric units; agreement on primary prophylaxis; designated trained physiotherapist in each district; recognition of hemophilia "cells" and "mother cell", staging the first WFH-TIF nursing course with local and national endorsement. A second patient government summit (2-Jun-2012) audited and ensured implementation in each hospital. As yet, genetic testing and inhibitor case management remains unsolved due to system and territorial inertia.

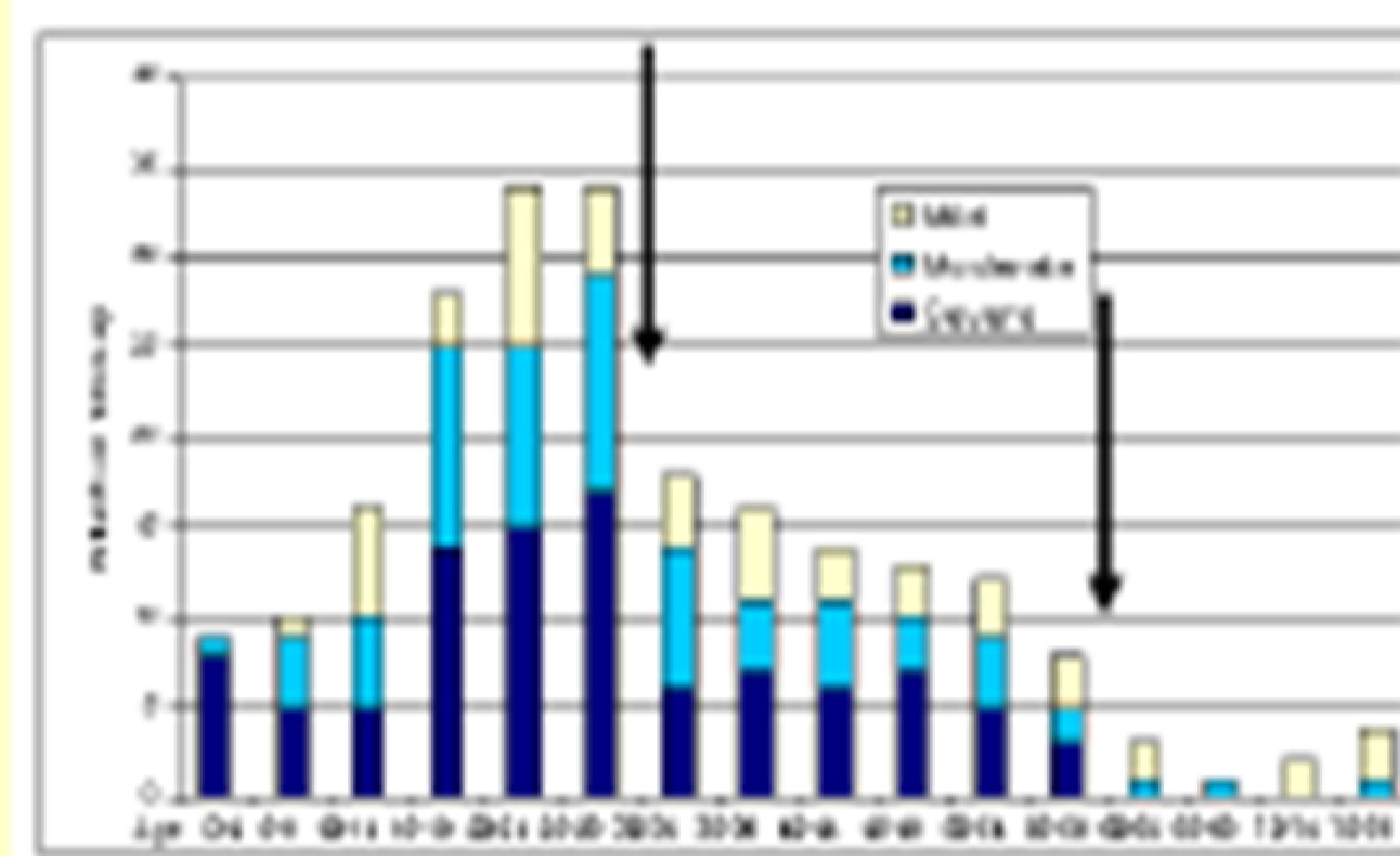
## CONCLUSIONS

Despite competing needs, through patient empowerment, catch-up efforts in standards of care can be achieved in affluent societies within reasonable time.

## Reference

Au WY, Lee V, Kho B, Ling AS, Chan D, Chan EY, et al. A synopsis of current haemophilia care in Hong Kong. Hong Kong medical journal = Xianggang yi xue za zhi / Hong Kong Academy of Medicine. 2011;17(3):189-94.

### Longevity in moderate and severe cases



75% of hemophilia are adults, they no longer die at 30-60

