Patient Involvement in HTA in China

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Objectives

- This presentation introduces the present situation of patient groups (associations) and general organizational structure in China, their function on HTA, health promotion and lobbing with third party payer
- The patient's empowerment will be strengthening in the future.

Methods

- A systematic review is made on the charters of different patient groups from the Chinese website. The authors discuss with key informants, including doctors, pharmaceutical companies and head of patient groups

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Research Findings

- According to the unofficial data source, more than 70 different kinds of disease patient groups have been established in China yet
- Some are registered by Ministry of Civil Affairs at national level; some are organized by hospitals at local level
- The patient groups or associations are self-organized by patients and their family members

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Role of Patient Involvement

- Their characteristics are voluntary basis, non-profit and mutual help
- The patient association plays a role as a communication platform to help patients each other
  - — Conducting health education
  - — Exchanging their treatment experience and psychological comfort
  - — Calling on government to focus on their diseases
  - — Improving the reimbursement and payment from third-party payer and PAP program
  - — Paying attention on the shortage of drugs, etc.

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Two Case Studies

1. The importance of selection on treatment therapy strategy for hemophilia A, on-demand treatment vs. prophylaxis treatment through the Hemophilia Home of China
2. Familial hypercholesterolemia is a severe dominant hereditary disorder of metabolism, now it has established a HoFH Chinese Care Center, more than 60 HoFH probands and their families have been awareness and followed-up

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Hemophilia Home of China

The Hemophilia Home Of China

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Hemophilia Home of China

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Current Situations of Hemophilia in China

- Main problems that haemophilia has:
  - —Lifelong high costs of treatments
  - —Insufficient reimbursement of the costs
  - —Shortage of medicine supply
  - —Discriminating education policies
  - —Family members or society do not understand or accept hemophilia A

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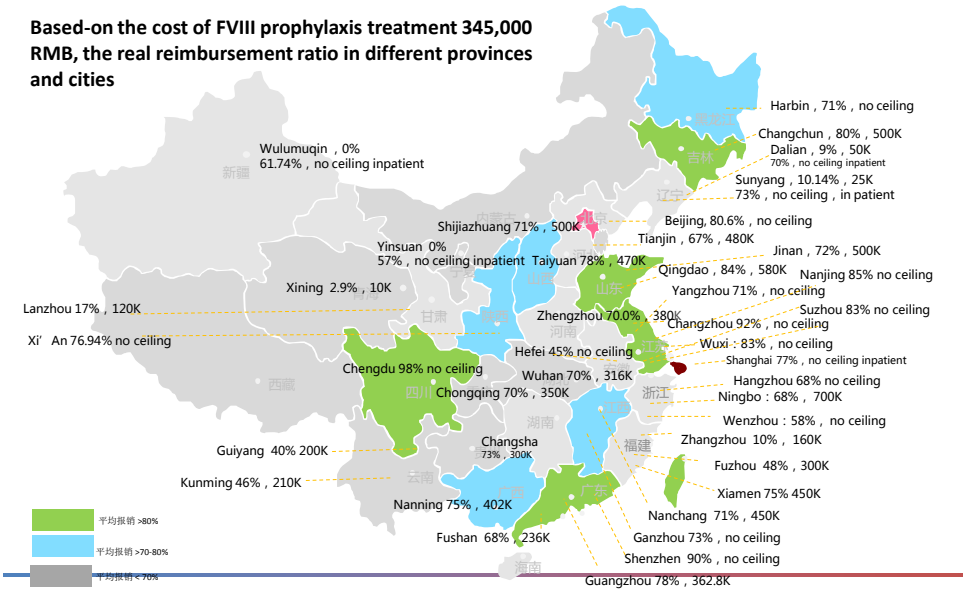
Reimbursement Map of FVIII Prophylaxis Treatment in China



(Bayer Co. 2016)

Advocating Medical Insurance Policies

2004 -- Hemophilia Home called for the inclusion of blood-coagulation factor into MOSS medical insurance drug reimbursement list

2007-- There was a national shortage of clotting factor VIII, called on relevant Ministries to care for the survival of Chinese hemophilia patients

2009 -- Made a proposal to National Development Reform Commission to set rational prices of bloodborne clotting factors

2010 -- Proposed to Ministry of Health to include hemophilia treatment drugs into NEML

2014 -- Made a proposal to the MoHRSS to cancel restrictions on the use of recombinant coagulation factor VIII

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The Contribution from Hemophilia Home of China

- 4665 hemophilia cases and family members have registered at Hemophilia Home of China
- Hemophilia Home has provided direct assistance nationwide (including medical aid, poverty relief, drug donations) for poverty stricken and severe hemophilia cases in 21 provinces and has helped 249 hemophilia cases
- In 2014 China Hemophilia Home won the World Federation of Hemophilia Outstanding Contribution Award

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Chinese Familial Hypercholesterolaemia Care Center

FH
CHINESE FH CARE CENTER
中国家族性高胆固醇血症关爱中心

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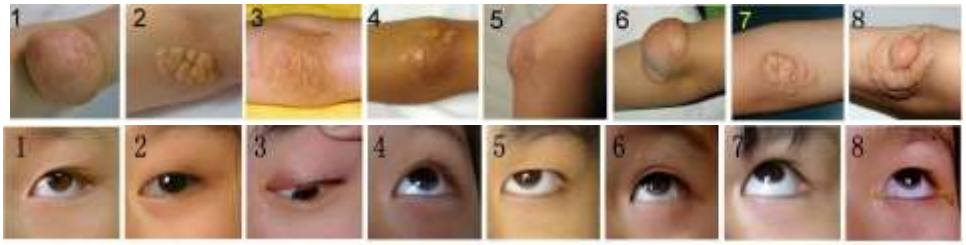
Clinical Profile of FH

- FH is a rare disease and a severe dominant hereditary disorder of metabolism, China may have 5,000 – 8,000 HoFH patients, but less than 100 index probands were found
- FH is the most important risk factor for CAD, early diagnosis and reduce LDL-C, can prevent it
- Tendon xanthoma and corneal arcus (due to cholesterol deposits)



(Luya Wang 2016)

Treatment Costs of Homozygous Familial Hypercholesterolemia in China

Drugs	Rosuvastatin	Atorvastatin	Probucol	Zetia	Day（RMB）	Year（RMB）
mg/Tab	10	20	0.5	10		
Price per Tab	8.87	10.10	1.71	9.35		
Age ≥ 10	√		√	√	25.1	9147
Age < 10	8.87 x 0.5		1.71 x 0.5	9.35x 0.5	12.5	4574
Age ≥ 10		√	√	√	26.3	9596
Age < 10		10.1 x 0.5	1.71 x 0.5	9.35x 0.5	13.2	4798

- **The economic burden of every HoFH family on treatment costs is nearly 20,000 RMB ($ 2,900 USD) per year**

(Source: Luya Wang et al, 2016)

The Establishment of Chinese FH Care Center

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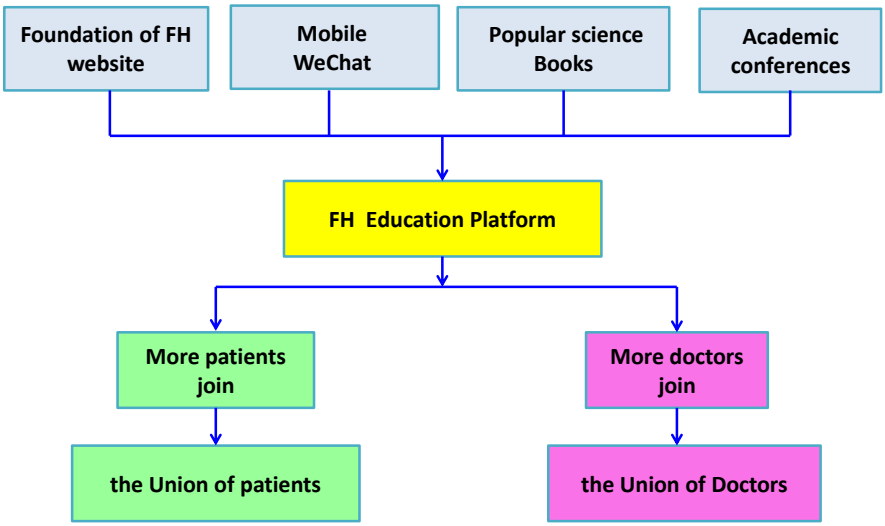
China FH campaign

The Establishment of Chinese FH Education Platform



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Research Findings in HoFH Probands

HoFH probandsi	Index	HoFH probands
General characteristics	Number of cases	66
	Age (Years)	13.8±9.6
	Male (n, %)	30 (45.5%)
	Xanthoma(n, %)	66 (100%)
	Corneal arcus (n, %)	29 (43.9%)
History	Smoking (n, %)	8 (12%)
	CAD (n, %)	11(16.7%)
	DM (n, %)	0(0%)
Ultrasound	MR (n, %)	22 (33.3%)
	AR (n,%)	25 (37.9%)
	AC (n,%)	26 (39.4%)
	IMT (cm)	0.18±0.06
	CVFR	1.78±0.56↓
Lipids before treatment	TC (mmol/L)	17.4±3.9 ↑
	LDL-C (mmol/L)	14.3±3.2 ↑
	TG (mmol/L)	1.4±0.6
	HDL-C (mmol/L)	1.5±0.9
Initial treatment	Statin	31 (47%)
	Statin + Zetia +Probucol	18 (30.3%)
	Other lipid-lowing drugs	15 (22.7%)

(Luya Wang et al: 2016)

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China has begun to pay attention to HoFH

- **2016.5 : Chinese Medical Association and Cardiovascular Health Research Institute launched the FH outpatient screening program ;**
- **2016.7 : The Chinese Ministry of science and technology approval rare disease precision medicine project (included FH) ;**
- **2016.8 : The establishment of a Chinese FH Care Center**
- **2017.2 : The health economics research program of HoFH has begun ;**
- **2017.3 : The establishment of WeChat public number of FH.**

The near future: the establishment of China's FH site, to join the global FH organization, to promote the government's reimbursement for patients, etc..

Conclusions

- The concept of people-oriented and patient-centered in China’s health system reform promotes the development of HTA and Pharmacoeconomics
- Patient involvement will be a critical issue when making policy in health insurance and value-based service delivery. Patient participation on making clinical decision needs to be awarded
- Finally, it will improve the relationship between doctors and patients


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