Hemophilia Care in China
Past, Present and Future

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China Hemophilic Patient
2013 IPPC
Population and Patients

- PRC Population: 1,370,536,875
  - Diagnosed: 10,652
- Taiwan Population: 23,000,000
  - Diagnosed: 980
- Large Gap
Diagnoses

- In 1953, first hemophilia A was diagnosed in Shanghai Ruijing Hospital.
- Now, almost all provincial capitals are capable in diagnosing Hemophilia A & B, but VWD is still limited to some advanced labs.
Products

- First vial of FVIII concentrate appeared in the early 1970’s by Shanghai Institute of Biological Co.
- 8 RMB yuan for 100 IU, equal to the lowest living standard for a month in Shanghai. Now is about 430 yuan = 200 IU plasma derived FVIII
- NO virus-inactivated process of any kind then
Products

• In between 1995-1996, virus-inactivated products suddenly appeared in the market and former products (no virus inactivation) disappeared instantly.

• At present, Hemophilia related products
  • FVIII -----4 companies (1 new)
  • PCC--------5 companies (1 new)
Supply

- Annual quantity of FVIII in 2010 was about 270,000 vials with 200 IU each = 54,000K IU
- Bayer’s Kogenate sold 65,000 vials, each 250 IU in 2012 = 16,250K IU (confirmed)
- Advate is on the market in 2013
- New brand of plasma-derived FVIII concentrate was on the market from Shandong province, yearly estimated 20,000K IU
Why Low Output?

- Because of past experience, fractionators still fear the risk of viral contamination.
- High tech in production control.
- Not much profit attraction before, but after the price increased, seems more companies have interest.
- After cryoprecipitate between 2 companies can be deployed via SFDA, the shortage of raw material is not an excuse.
Treatment

• HTC are in almost all provincial capitals

• Standard HTC is few, Guangzhou, Beijing

• FFP, Cryo, FVIII, PCC, rFVII, Recombinant

• Surgery, Joint Replacement, Huge Pseudo-tumor Removal, etc.

• Radio synovectomy

• Arthroscopic surgery
Policy

- No national unified policy on the medical health care based on equality and fairness.
- Ministry of Labor (hundreds of billions)
- Ministry of Health (no money)
- New Rural Cooperative Medical System (NRCMS) which is administrated by provincial governments and directed by the State Council (billions)
Drug List

- Ministry of Labor and Employment
- FVIII (plasma-derived) is in A class, covered by the proportion of reimbursement
- FVIII (recombinant) is in B class, must pay 10% before entering reimbursement, and only be used under circumstance of no plasma-derived FVIII is available.
- Money controlled and limited to government owned hospitals
Drug list (2)

- New rural cooperative medical system
- FVIII, PCC included, FFP not included
- No guideline or restriction between plasma-derived and recombinant products
- Hemophilia is listed as serious disease; i.e., in-patient and out-patient can get same high percentage of reimbursement rate.
Reimbursement

- All reimbursements depend on patient’s hukou (household / resident registration) and social identities
Reimbursement (2)

- Government employee, urban employee, government-owned companies’ employee, retired employee, urban resident without employed, handicapped, infant & students under age of 18, university student, retired government-owned companies’ employees returning hometown after supported remote countryside, etc.
New Rural Cooperative Medical System

- Administered by individual province or regional district separately
- Annual max amount 100,000 Yuan (RMB) = Approx. US$15,000
- Co-payment by individuals and local government
Examples

- Beijing, children under age of 18 can have 70% reimbursement
- Shanghai, children under age of 18 can have reimbursement 50% from local resident medical care system & another 50% from Shanghai Mutual AID Foundation of Children Severe Diseases, free up to a max amount of 200,000 Yuan (RMB)
Service

- To reduce the speed of increasing expenses on medical insurance, the administrations make contractual budget with hospitals and refuse to pay the exceeded amount.
- Factor concentrates are still not easy to get
- Hospitals are still the main source for getting factor concentrates, not drug stores.
- Hopefully, the present health-care reform will be able to change these shortfalls
Epidemic events

- Before 1995, FVIII concentrate was not virus-inactivated
- SIBP produced 200,000 vials in almost last 20 years, 10,000 patients used
- Near 100 patients has been infected with HIV in Shanghai whereas HCV is extremely high for those above 30 years of age
- HCV varies from 20-50% at national level.
- In HIV high prevalence provinces, HIV positive from FFP or Cryo are also seen.
Patient organization

- Hemophilia Home of China set up in 2000
- China Hemophilia Rehabilitation Federation [www.cnxueyou.org](http://www.cnxueyou.org)
- 25 Provinces, 6 registered
- Combine effort in appealing for some compensation on HCV infection
- Advocate to release the importation ban on foreign plasma-derived products, especially factor concentrates
Ideal Future

- Secured supply, affordable, reachable
- Different products to meet different requirements/symptoms
- All HTC meet their definitions
- Policy advocacy obstacles to be reduced
Thank You!

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