

First Plenary Session
**HEARING THE PATIENT'S VOICE IN
HEALTH CARE DECISION MAKING IN ASIA**



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Beijing, China

DREAM AND HOPE



Hemophilia Home of China (HHC)

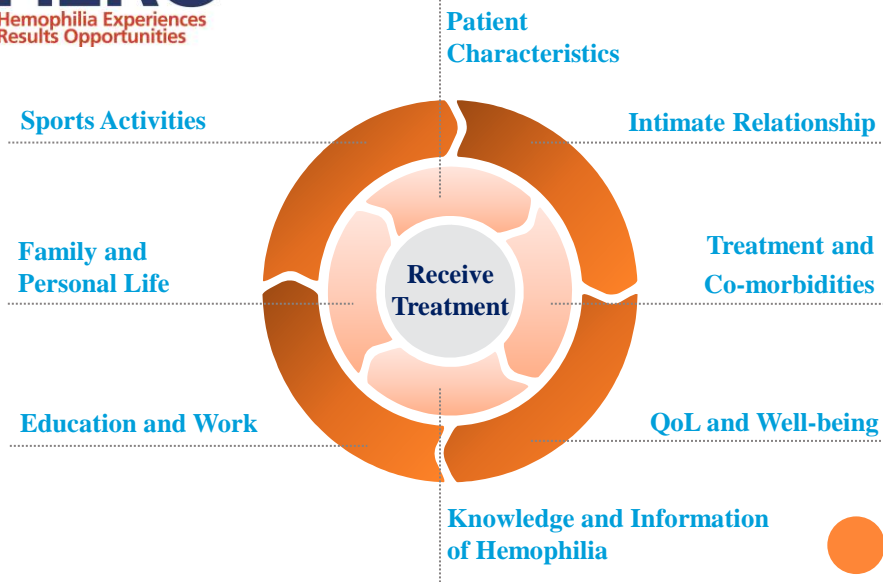
Tao Guan
General Secretary
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WHAT IS HEMOPHILIA



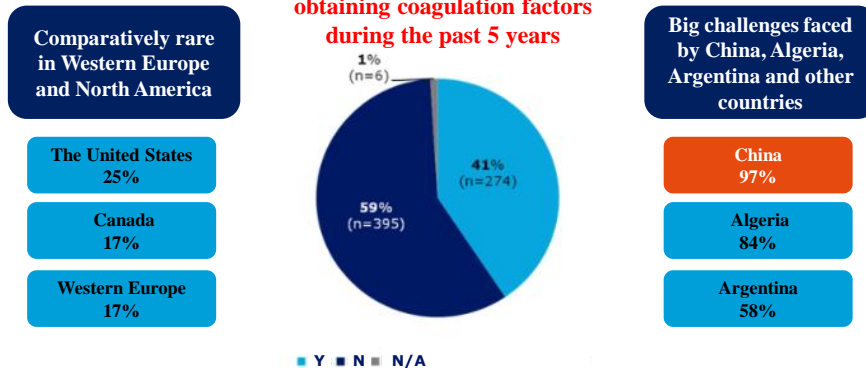
ALEX DOWSETT





LIMITED ACCESS FOR COAGULATION FACTORS EXISTS IN MANY COUNTRIES BECAUSE OF SHORT SUPPLY OR FINANCIAL DIFFICULTY

Patients reported difficulties in obtaining coagulation factors during the past 5 years



PATIENTS WITH HEMOPHILIA IN CHINA



www.xueyou.org

HEMOPHILIA HOME OF CHINA (HHC)

A cooperative organization formed spontaneously by patients with hemophilia. Nearly 5,000 hemophilia patients had registered in HCC in China.

2000

Founded in 2000 and focus on patient education

2004

Advocate for the change of local health insurance policy in 2004

2009

Advocate for the change of national health insurance policy in 2009

2012

Became a charitable organization in 2012

Focus on publicity since 2000

THE MEDICAL INSURANCE IN CHINA

Universal medical insurance coverage has been achieved in China by 2013

- Urban Employee Basic Medical Insurance (UEBMI)
- Urban Resident Basic Medical Insurance (URBMI)
- New Cooperative Medical Scheme (NCMS)

Mainly focus on hospitalization reimbursement.

WHAT WE HAVE DONE

Local government relevant departments

National government relevant departments



HHC began to communicate with some local social security institutions across China in 2004, hoping to list hemophilia as special outpatient disease (higher reimbursement rate).

HHC began to make coverage suggestions to the national government departments directly in 2009.

THE MEDICAL INSURANCE AMONG PATIENTS WITH HEMOPHILIA IN CHINA

China has achieved universal medical insurance coverage among patients with hemophilia A by 2013.

- UEBMI
- URBMI
- NCMS

Medical costs incurred by patients with hemophilia A who were enrollees in each of the three medical insurances above can be reimbursed.

THE MOST PRESSING DIFFICULTIES ON MEDICAL INSURANCE

- Lack of the reimbursement policy for hemophilia B patients combined with antibody hemophilia.
- Lack of supply of pharmaceuticals.
- The reimbursement of hemophilia is still only for hospitalization treatment in many cities.
- The out-of-pocket expenses for patients with lifelong disease are still considerable.

Thank you!

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Hemophilia Home of China

