

# 蝴蝶宝贝关爱中心 DebRA-China

TM

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# Agenda

1. Epidermolysis Bullosa
2. Why to set up DebRA-China
3. History, vision and focus
4. Organization
5. Results

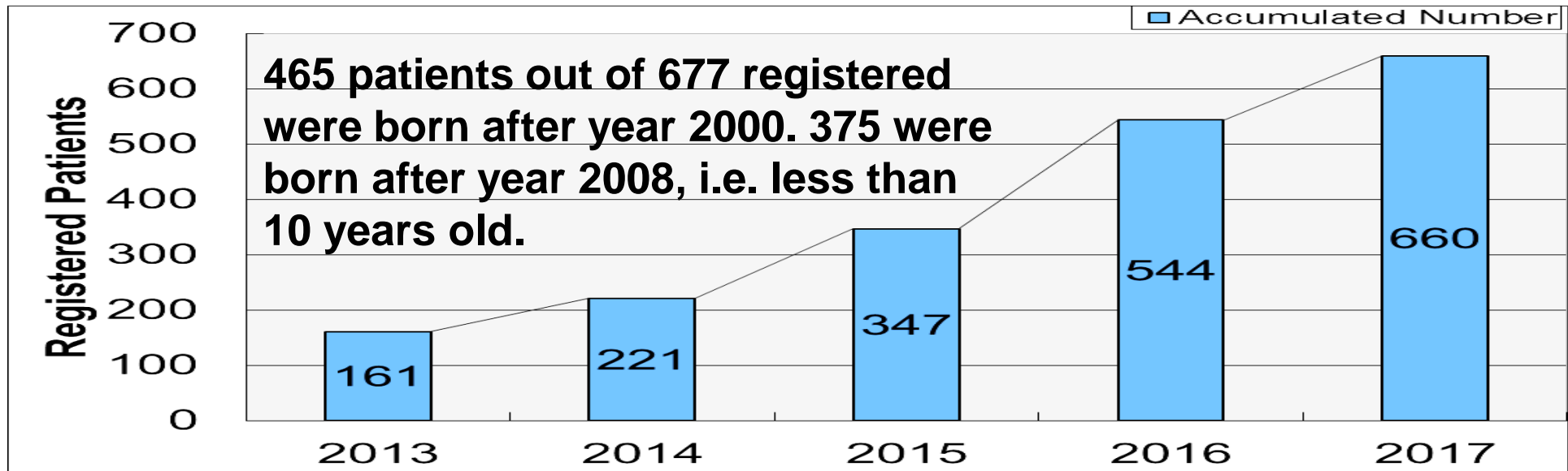
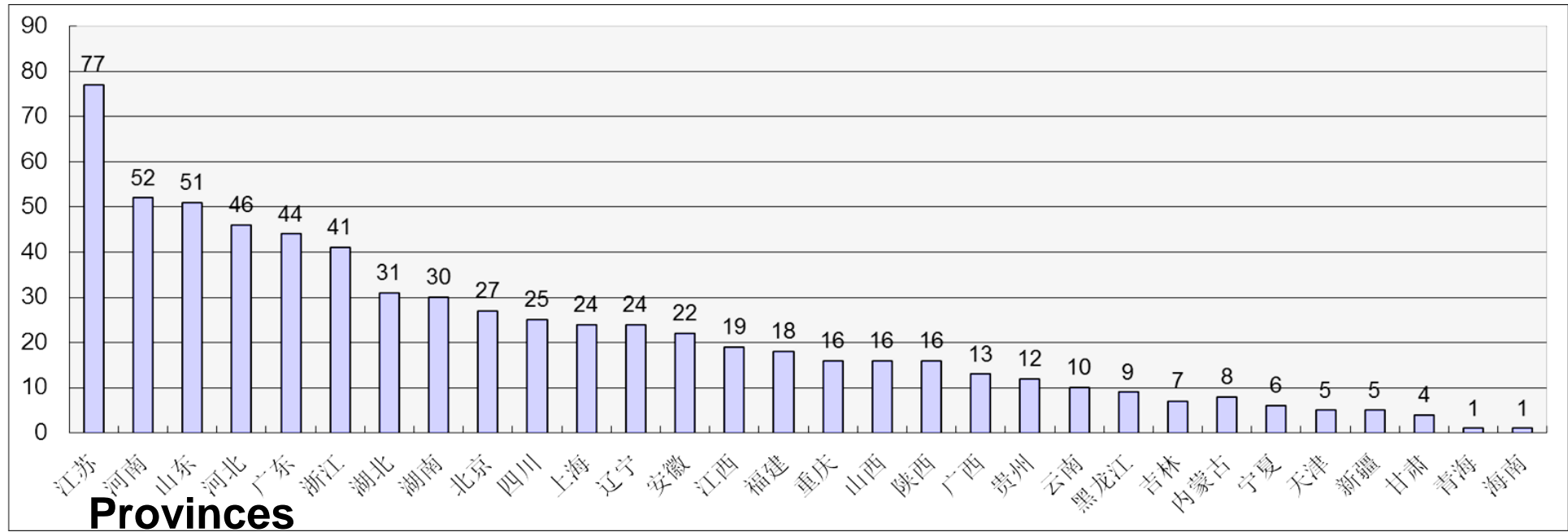


# Epidermolysis Bullosa



inherited Epidermolysis Bullosa (EB):  
EB patients have fragile skin, blister and wound during daily life, and the disease is incurable. EB can show and be diagnosed at born, Majority of EB patients in China is Children.

# Registered Patients in China



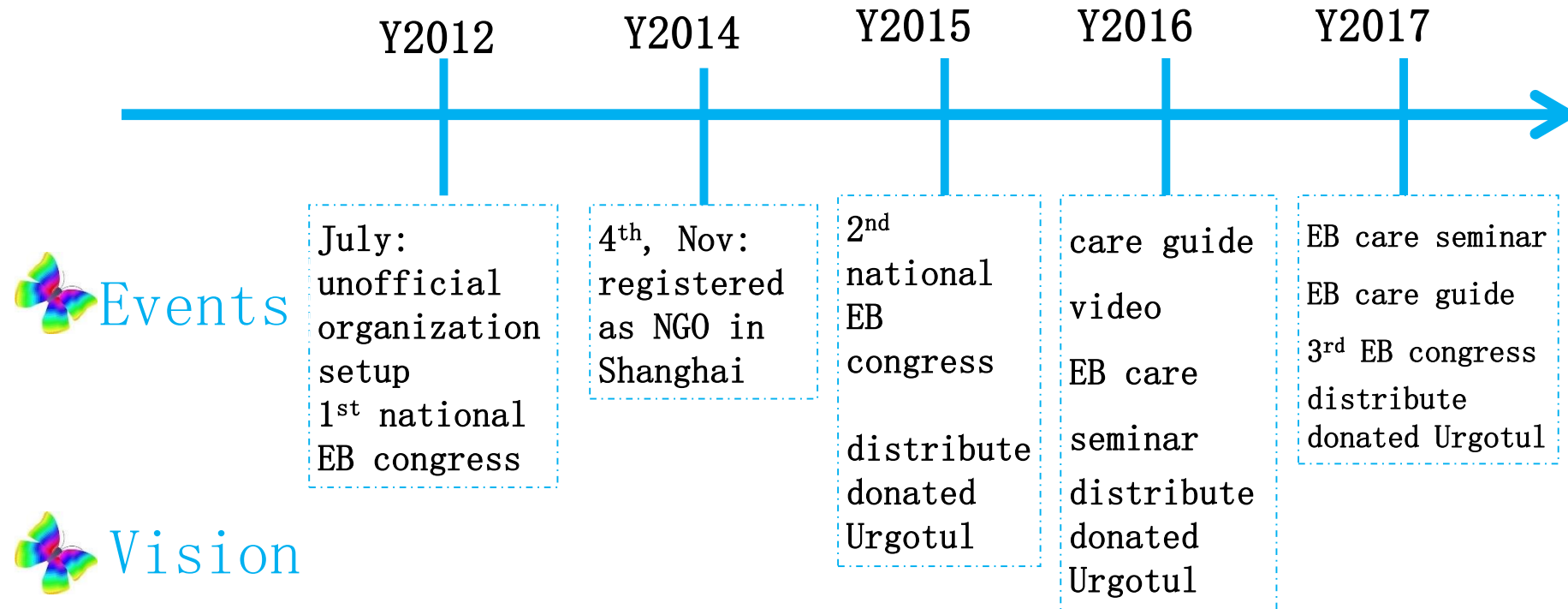
# Why to set up DebRA-China?

Back in 2006/2012, knowledge and doctors were rarer than EB patients in China.

Patient families wanted to help each other, share experience, appeal for proper medical care and general support from people and government.



# History



## Events

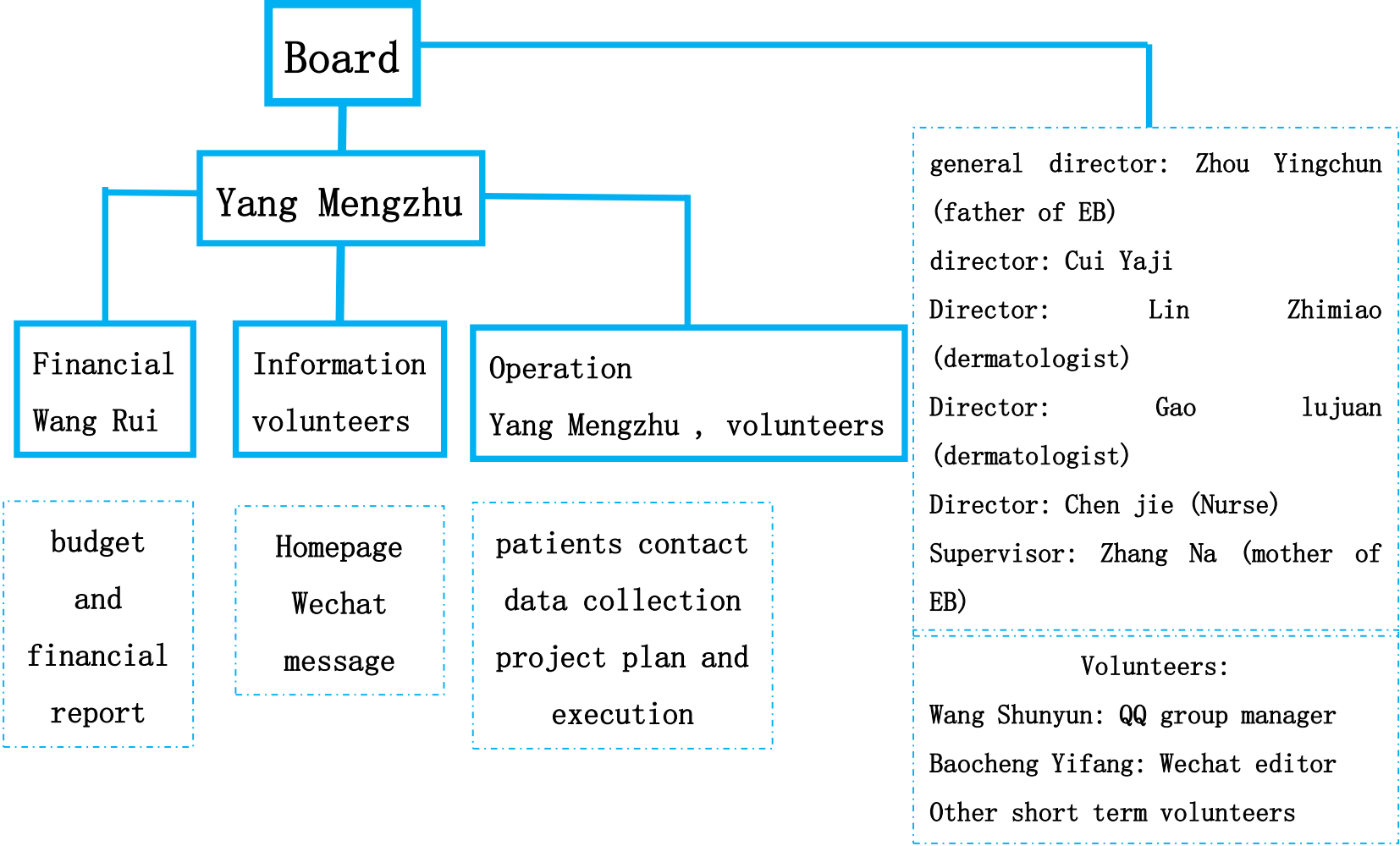
## Vision

Improve medical treatment, study, working, daily life and social quality steadily for EB patients and families

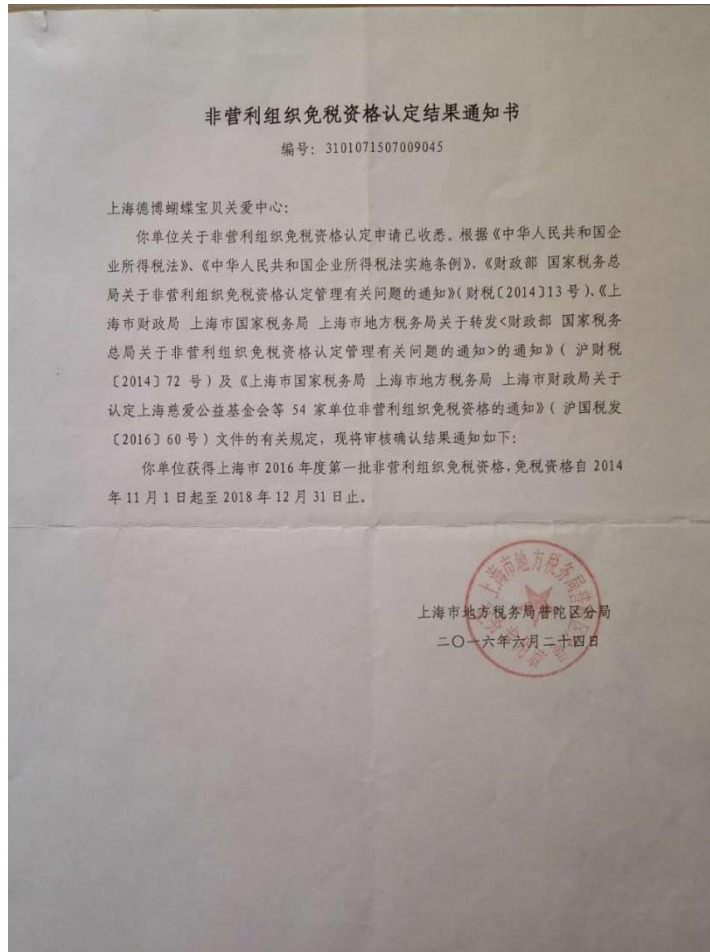
## Focus

Help EB patients and families, spread EB knowledge, advocate for better medical treatment

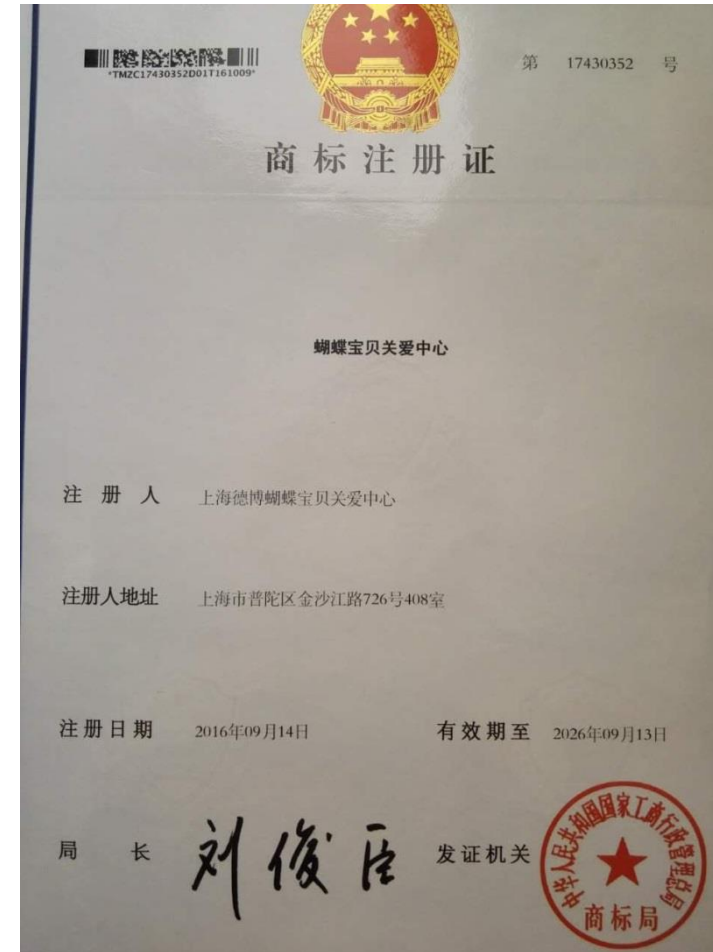
# Organization



Tax exemption authorized  
by Shanghai tax bureau  
in year 2016



Trademark  
registered





# Service Provided - For patients and carers



**Doctor Map**

寻找专业医生



**Free consult**

享受专家义诊



**EB Care seminar**

专家面授护理技能



**EB Care guide and video**

自学护理方法



**EB congress**

与病友当面聊



**free gene diagnose**

免费基因检测



**EB baby starter package**

新生儿护理包



**dressing donation**

免费领取敷料

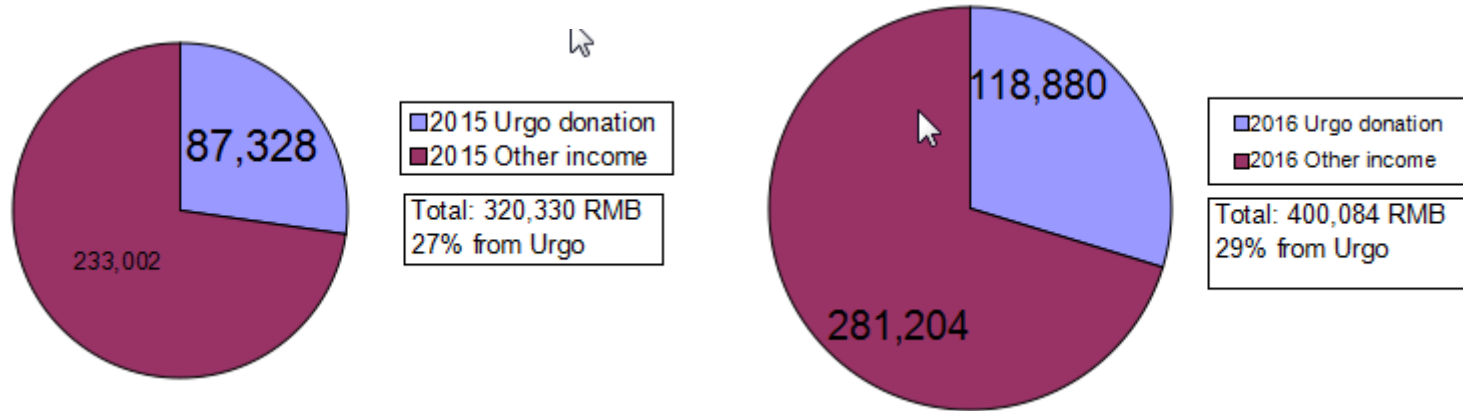


**in-patient allowance**

住院慰问金

# Organization weakness

- fund mainly depend on Urgo foundation



- no proposal to insurance policy yet
- limited publicity
  - missing a short animation
  - limited coverage in news media
- Staff no enough
  - financial officer changed two times
  - lack of long term volunteers, no adult patient
  - Only one full-time employee

# Organization strength

- As the Only EB NGO in China, we have best knowledge for the disease, patients, research status, and market opportunity.
- Official registered, cooperation with several foundations.
- a group of top EB expert in China.
- Information publicity: financial report and board meeting minutes available in homepage.
- Strong support from Shanghai patients families.

# Good time to affect policy in China

- Oct. 8<sup>th</sup>, 2017, the Central Committee of the Communist Party and the State Council jointly published <<opinion to reform approval and encourage medicine and instruments innovation>>, which mentioned:
  - support medicine and instrument development for rare disease
  - publish rare disease catalogue, set up rare disease patient register
  - orphan drug and instrument approved abroad can skip clinical trial and be approved conditionally.
- What should we do?
  - 1, Ensure EB is included in rare disease catalogue
  - 2, Help EB research and clinical trial
  - 3, Advocate EB dressing and drugs to be covered by insurance

# Contacts

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