



NGO COMMITTEE FOR
RARE DISEASES

What can Taiwan Contribute to the UN Sustainable Development Goals 2030 : A NGO Model for Rare Diseases

Min-Chieh Tseng

Co-founder, Taiwan Foundation for Rare Disorders

Dean, College of Social Sciences, National Taipei University

A Committee of CoNGO



CoNGO
The Conference of NGOs
in Consultative Relationship
with the United Nations



TAIWAN

- **Location:** East Asia
- **Area:** 36,000 square kilometers
- **Population:** 23 million
- **Ethnic groups:** 84% Taiwanese (including Hakka)
14% Mainland Chinese
2% Aboriginal Population



A Story of Borrowing Orphan Drugs in 1993

- In 1993, I borrowed a critical orphan drug for saving my son from Mrs. Serena Wu, who was also a mother with a rare-disease child.



A Frustration of Lobby in 1997

- In 1997, Serena Wu & I tried to lobby the Taiwan National Health Insurance for reimbursing the cost of orphan drugs, but we failed.

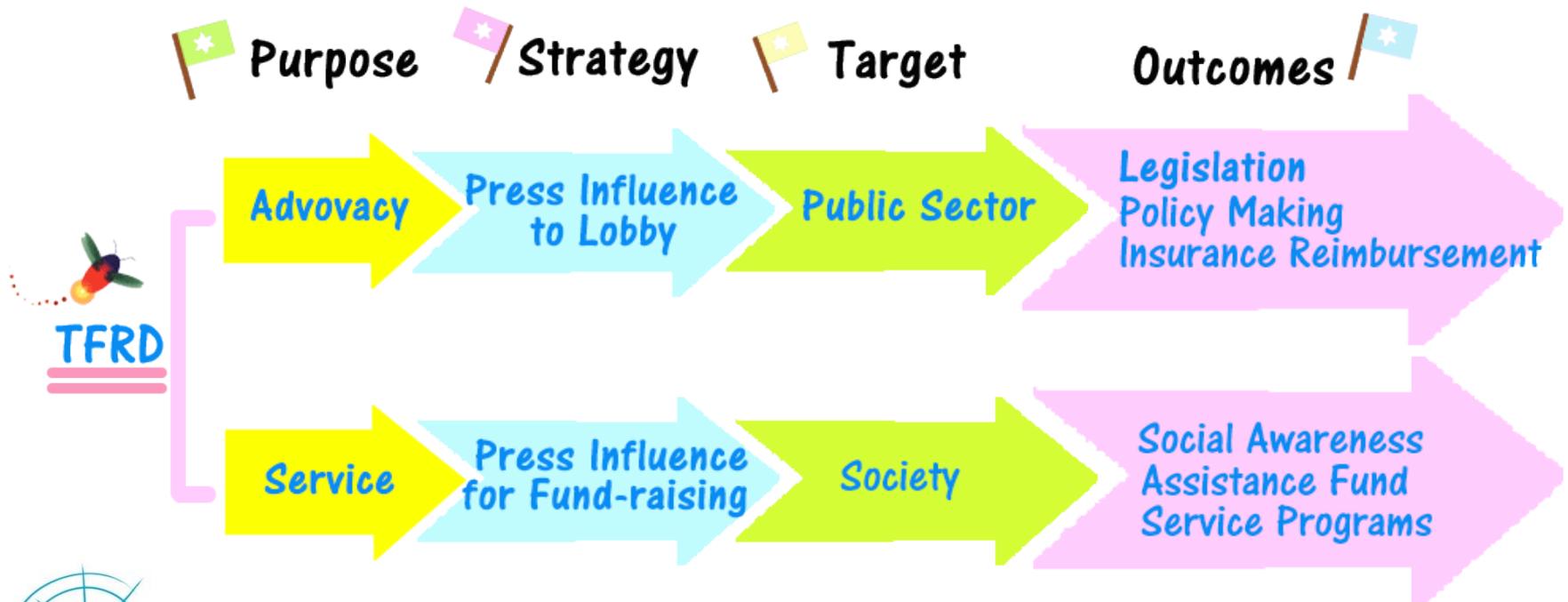


A Patient-led NGO Started in 1999

- Taiwan Foundation for Rare Disorders (TFRD) was established in 1999.
- TFRD mainly focused on “patients & families” rather than on “drugs or treatments.”
- Since 1999, TFRD has been an active force in Taiwan to raise the quality of life for rare disorders.



A NGO Model from Advocacy to Service



Advocacy Outcome in Public Sector

- In 2000, the Rare Disease and Orphan Drug Act was passed by the Taiwanese Congress.
- In 2000, orphan drugs have been reimbursed by National Health Insurance.
- In 2001, rare disorders were covered by the "Physically and Mentally Disabled Citizens Protection Act" to access social welfare benefits.



Life is Changing due to Advocacy

1999



Nowadays

**National
Health
Insurance Act
2000**

**Physical &
Mentally Disabled
Citizens
Protection
Act
2001**

**Rare Disease and Orphan Drug Act
2000**

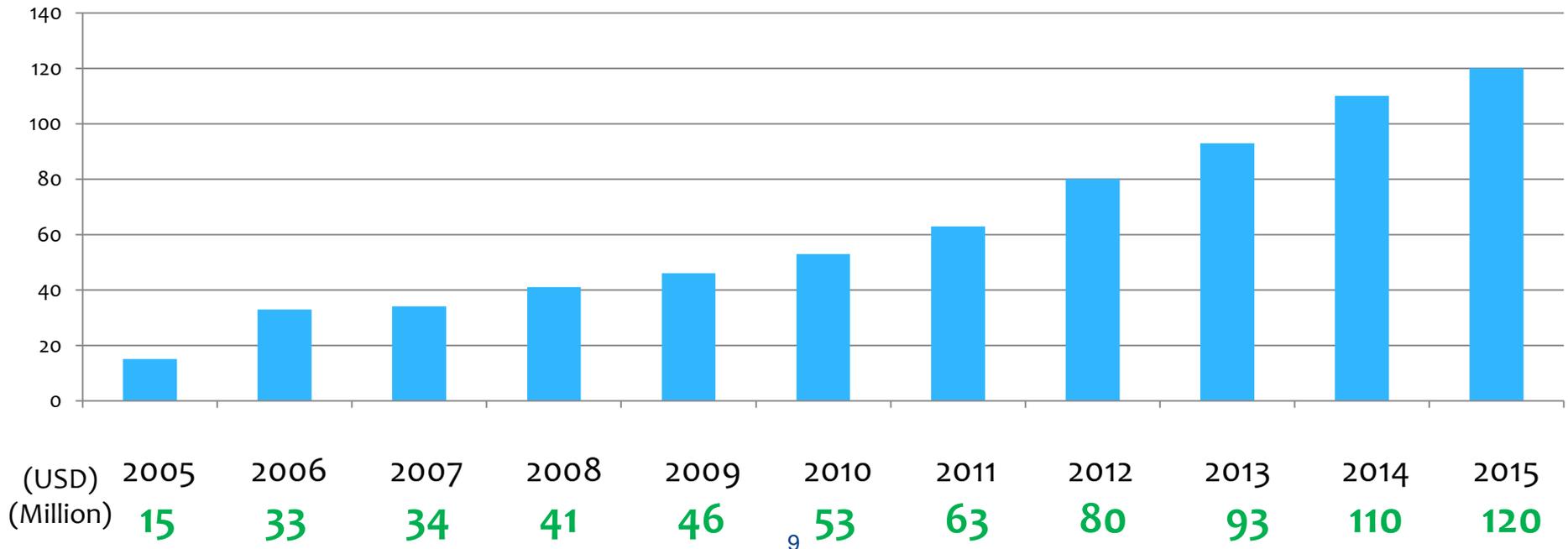


Law & Policies have been
established to support patients.



The Budget of Rare Disease is Bigger

Medical Expenses and Orphan Drugs fee of National Health Insurance for rare disease has increased from 15 millions of 2005 to 120 millions of 2015.



Social Awareness on Rare Diseases In Media

1999

On average, only 100 reports annually about rare disease from 1996 to 2000.

Nowadays



There are 513 reports about rare disease in 2016.



More Patients Join TFRD

1999



- TFRD served about only 100 patients with 23 rare diseases in 1999.

No diseases were recognized by government.



Nowadays



- TFRD served about 7,000 patients with 248 rare diseases now.
- 215 diseases were recognized by government.

The Donation of TFRD is Increasing

1999



- In 1999, the donations for TFRD was 0.36 million US dollars, from about 5,000 people.

Nowadays

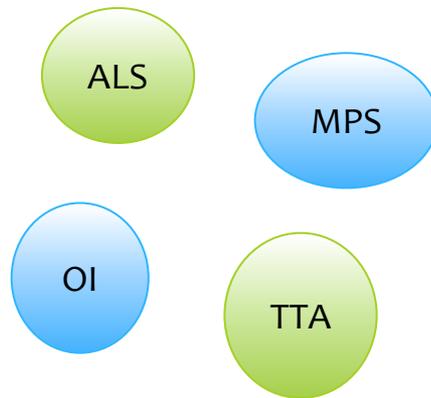


- In 2015, TFRD got donations of 5 million US dollars, from about 90,000 people.
- About 86% of annual donation comes from a single amount of \$32 or lower, without any funds from government.



The Patient Groups are Stronger

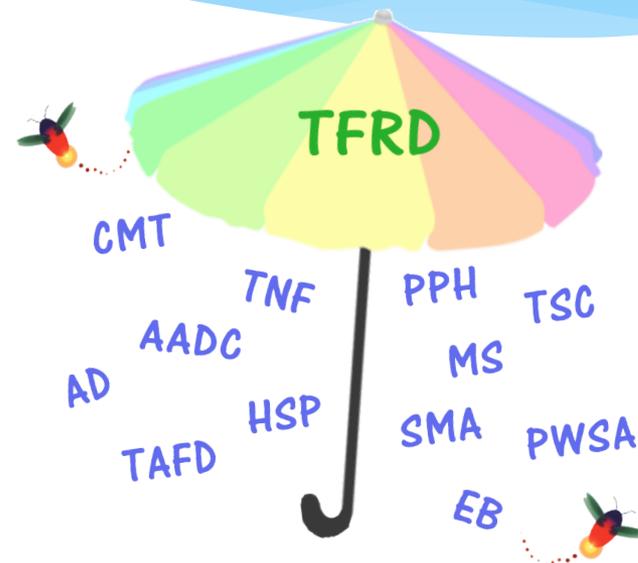
1999



- There were just 4 patient groups for rare disorders in 1999.

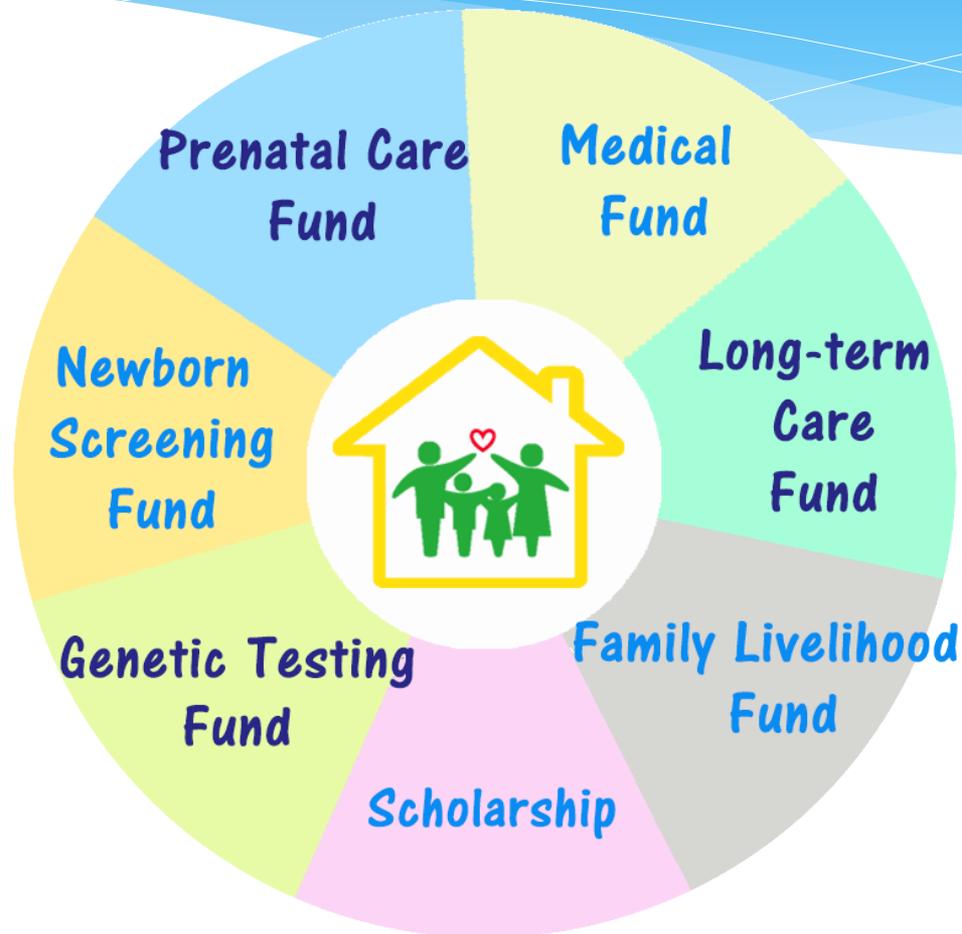


Nowadays



- TFRD has assisted 31 patient groups to become legal associations or informal groups in the past two decades, also providing with 2.3 million US dollars.

TFRD Assistance Funds Including...



TFRD Service Programs Including...



Psychological
counseling

Rehabilitation
Service



Art
Therapy

TFRD Multi
Service program

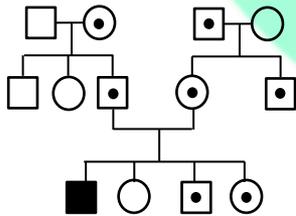


Nutrition
Care



Genetic
Counseling

Recreational
Program



TFRD Prevention Programs

- Since 2000, TFRD started to promote Expanded Newborn Screening with a financial support.
- TFRD have supported prenatal genetic testing and counseling for 380 rare disease families from 2006 to 2015.
 - 90% newborns are without rare diseases.



Conclusion: TFRD's 7 Keys Including...

- Passion
- Parents
- Patient Groups
- Press
- Policy
- Program
- Prevention



(Former President Ma)



(President Tsai)

