



NGO COMMITTEE FOR
RARE DISEASES

JAPAN

Trackling Rare Diseases Internationally Through National and Regional Strategies
The Global Gathering for Rare Diseases;
Inauguating the NGO Committee for Rare Diseases

Yukiko NISHIMURA
President of NPO ASrid, JAPAN

A Committee of **CoNGO**



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



Patients use 'NANBYO' in Japan

3 TARGETS of NANBYO Patients

NAN
難
Difficult

BYO
病
Disease



Patient of **Rare disease**



Patient of **Intractable Disease**



Patient who faces problems causing difficulties in his / her social life by **(chronic) disease**



Recent Progress of NANBYO Policy / Challenge

Target Diseases	Target Basic Act	Number of Designated Diseases
Pediatric and Chronic diseases	Child Welfare Act(revised by 2014)	704 (Jan. 2015 ~)
NANBYO	NANBYO law (issued by 2014)	306 (July, 2015 ~) + 24 (April, 2017~) <i>*some of Pediatric diseases are the part of it</i>
Disability Persons	Comprehensive Supports for Persons with Disabilities Act (issued by 2013)	332 (July 2015 ~) <i>*some of NANBYO are the part of it</i>

Project	Organized by;
Initiative on Rare and Undiagnosed Diseases (IRUD)	AMED
National Conference for Patients and Families	Japan Patients Association, The Pediatric NANBYO network, etc
Rare Disease Day JAPAN	NPO ASrid (as a secretariat office)



Messages from Japanese leaders



Thank you for your attention!



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