

# Building a platform for exchanging patients' information among doctors, researchers and patients on J-RARE

Masatoshi Iwasaki<sup>1</sup>, Yukiko Nishimura<sup>1,3</sup>, Kunihiro Nishimura<sup>1,2</sup>, Shun Emoto<sup>1,4</sup>  
**J-RARE patient organization groups and Soichi Ogishima<sup>1,5</sup>**

1. ASrid 2. Graduate School of Information Science and Technology, The University of Tokyo 3. RCAST, The University of Tokyo  
 4. Graduate School of Health Sciences and Nursing, Faculty of Medicine, The University of Tokyo.  
 5. Tohoku Medical Megabank Organization, Tohoku University

## J-RARE is..

- Established as Patient registry (PR) and personal health record (PHR) service for rare and intractable diseases' patients in 2012.
- Developed and maintained by patients (patient groups) in cooperation with JPA (Japan Patients Association) and ASrid.
- Supported by Health and Labor Sciences Research Grant funded by MHLW (Ministry of Health, Labor and Welfare of Japan).

## Goal of J-RARE

- Rare and intractable diseases' patients managing their own PHRs to clarify their natural history.
- Bridging people who participate in studies both to reveal mechanism of pathogenesis and to develop drug for rare and intractable diseases.

### Target diseases as of Apr 2016

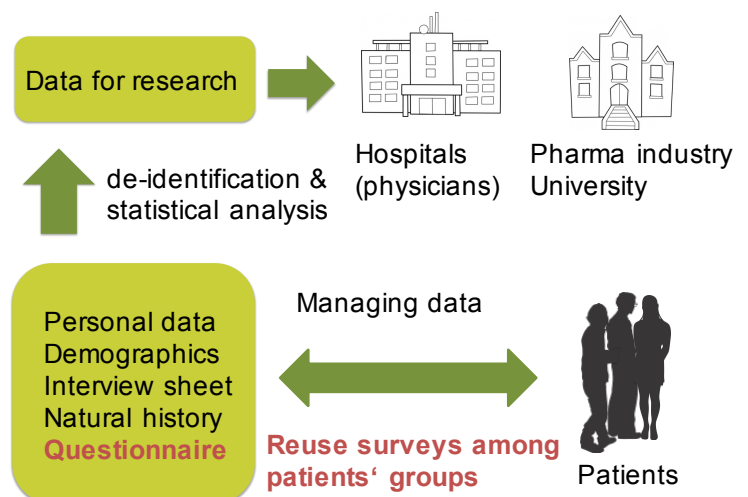
DM	Distal Myopathy	MFS	Marfan Syndrome
RP	Replacing Polychondritis	IS	Isaacs Syndrome
RSS	Russell-Silver Syndrome	MD	Mitochondrial Disease



## Planned new features in 2016: Data for patients and data for researchers

New findings from discussions and interviews with doctors, researchers and patients after the establishment of J-RARE.

	Doctors / Researchers	Patients
Findings from the interviews	Prefer to collect only specified data suitable for their research, not raw data provided by the patients.	Having difficulties to conduct surveys. Creating appropriate questions for surveys still requires a lot of work.
Solutions by J-RARE	Add a feature to collect necessary data by online questionnaire on J-rare.	Enable to reuse past surveys created by patients' groups joined in J-RARE.



### J-RARE patient organizations:

Miki Wada (Isaacs), Yuriko Oda (Myopathy), Kenichi Kondo (SRS), Keiko Inoi (Marfan), Michitoshi Watanabe and Ikuya Suginochara (Mito and KOINOBORI)

