

**RAISING AWARENESS AND TRANSFORMING LIVES  
OF THE 70 MILLION PEOPLE WITH RARE DISEASES**

**BE THE CHANGE YOU  
WISH TO SEE**



Organization for Rare Diseases India (ORDI), a non-profit Organization, founded in Feb 2014, with the mission to improve health of patients with Rare diseases through Awareness, Advocacy, Patient Support programs, Collaborations & Information dissemination

ORDI works to connect Rare disease patients, policy makers, medical fraternity and Health Care Industry

# Organization for Rare Disease India



ORDI is a patient – centered organization with a vision to make lives better for people with Rare Diseases & is a torch bearer for the Rare Disease (RD) community in India.

ORDI strives to be the collective voice for people living with RD in India, reduce inequalities & ensure equal access to health resources as any other population

For over 10 years, ORDI has been instrumental in bringing RD discussion into public forum, thus driving Government's attention

**Prasanna Shirol, Co-founder of ORDI**, has undergone an odyssey of 7 years to unravel his daughter Nidhi's diagnosis of Pompe, a rare disease. Having struggled medically & financially for 14 years to manage Nidhi's condition, he initiated many activities & co-founded ORDI (an umbrella RD organization) after realizing the absence of government support or policies to guide or bear the exorbitant burden of Rare diseases.

# Vision, Mission & Objectives

## Vision:

A Better Life for people with Rare Diseases

## Mission:

ORDI's mission is to be the strong united voice for all rare diseases in India, to reduce inequalities and ensure that people living with rare diseases have access to the same resources as any other population

## Objectives:

1. To promote Rare Diseases as human rights priority through public awareness.
2. To contribute towards development of Public Policy and take part in implementation, such as Rare Disease Policy and Orphan Drug Policy.
3. To collaborate with advocacy organizations from India, & people living with rare diseases; working jointly to connect them with national & international forums such as NORD, EURORDIS, RDI, Global gene, UDN
4. To accelerate diagnosis and treatment options for patients with rare diseases through public-private partnerships, and by advocating mandatory New Born screening
5. To Facilitate & encourage Clinical Trials, Research & Orphan drug development activities.



Organization for Rare Diseases India is committed to systematically & holistically address the challenges faced by RD community by engaging with key opinion leaders & Rare Disease experts nationally & internationally

## ORDI Care for Rare Webinar Series, SIAMG ORDI Webinar Series, and CMEs etc.



Advocacy | Awareness | Patient Support | Clinical Trials | R&D



RD Helpline



R D Camps



Patient support Program



COERD @IGICH -CHG



CME /Conference

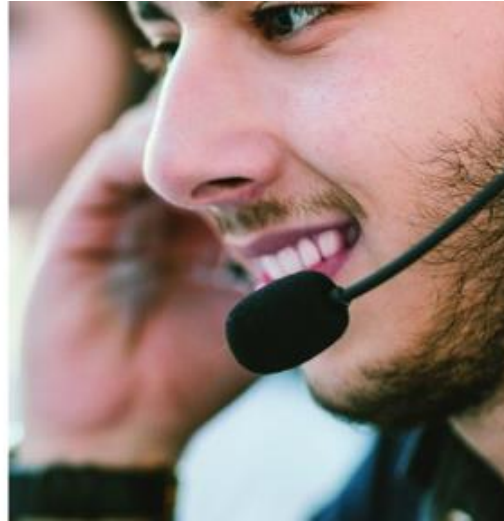
# Our Collaboration & Milestones

- ✓ Day Care Ward – (Centre of Excellence for Rare Diseases) at Indira Gandhi Institute of Child Health, Bengaluru & Centre for Human Genetics
- ✓ RDCCC at JSS Hospital (Mysore), Nerve & Muscle Clinic in Baptist Hospital (Blr)
- ✓ To support Non-Medical Patient Support Services, ORDI MOU with: AIIMS (Delhi), Centre for DNA & Finger Printing Diagnostics (Hyderabad), Sri Guru Ramdas University of Health Sciences (Amritsar), ICH (Chennai), SAT Hospital (Thiruvananthapuram)
- ✓ Over 11k patients associated. Facilitated over 375 treatments (Rs.280 Cr)
- ✓ Nearly 3400 doctors & 500 volunteers support our efforts. Working with 80+ PAGs worldwide. Over 2,100 advocacy interactions with Policy Makers
- ✓ Conducted 150+ webinars with over 7,000 webinar participants
- ✓ Around 12K calls attended at our India's first Rare Diseases Helpline
- ✓ Over 40K unique participants in Racefor7 supporting the cause of RD



## First Nationwide Rare disease Helpline +91 8892 555 000

We inaugurated India's first rare disease telephone helpline to help patients with rare diseases navigate their journey by connecting them with specialists and parent support groups, and the line has already received 9120 calls.



## First RDCCC (Rare Disease Care Co-Ordination Centre)

We've launched India's first RDCCC in Bangalore, with the goal of establishing critical infrastructure to connect patients with rare diseases and healthcare providers, disease area medical experts, recognised diagnostic centres, genetic counsellors, caregivers, treatment options, national and international clinical trials, and funding options where possible.



**RARE DISEASE**  
Care Co-ordination Centre

—ORDI Initiative—

## Race for 7- An annual mega Rare Disease Awareness 7 km Walk/ Run/ Ride in India.

Race for 7 symbolises the solidarity for the community that braves through over 7000 Rare Diseases. 2022 marks the 7th year of Racefor7. Racefor7 is the an unique national Rare Disease Day event that unites all stakeholders for a common cause - for Rare Disease Awareness, and for the Unheard to be Heard!



7000 Rare Diseases | 7000 meters

# Recognitions

## 2018 - Ashoka Fellow 2019 - Rare Champion of Hope

Our Executive Director and Co Founder was recognized internationally for his Rare Disease Advocacy through ORDI. He was awarded the prestigious Ashoka Award and the Rare Champion of Hope Award.



## 2022 APAC Business Award

Awarded the APAC Business Award for 2022

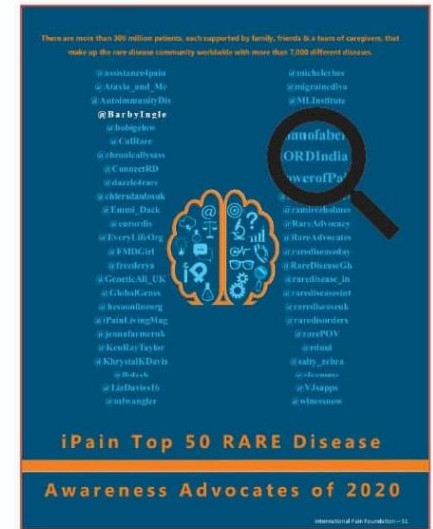
## 2019-2020 Hindu Changemaker

Recognizing the commitment of ORDI towards the Rare Disease Community, ORDI was nominated twice for the Hindu Business line Changemaker Award in the year 2019 and 2020.



## 2020 Top 50 Advocates Award

ORDI was recognized internationally for Rare Disease Advocacy by iPain and listed among the top 50 Rare Disease Awareness Advocates of the year 2020.



## Best Patient Support Rare Disease Company

ORDI was awarded "Best Patient support Rare Disease company in India" by Acquisition International

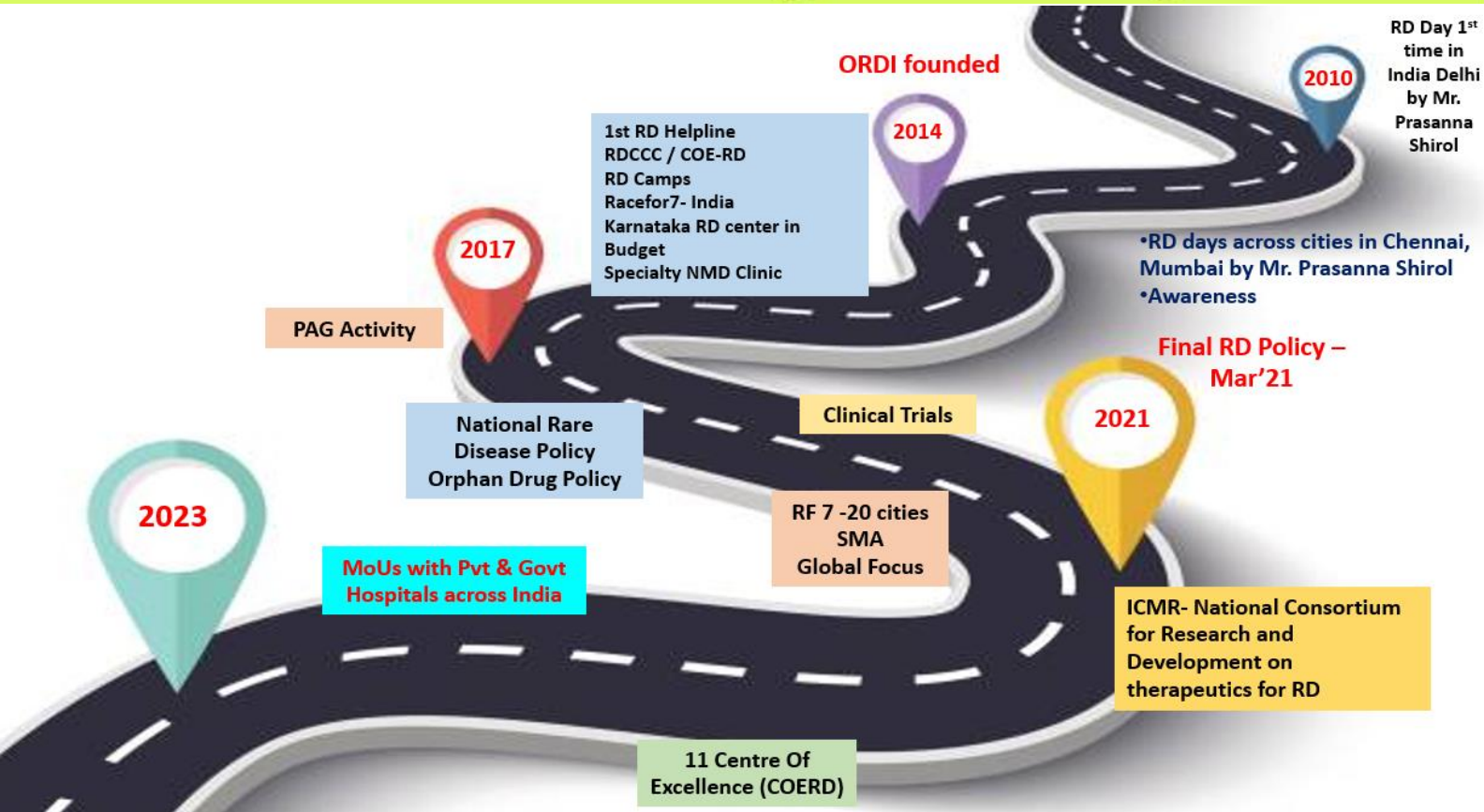


# Supporting the Cause...

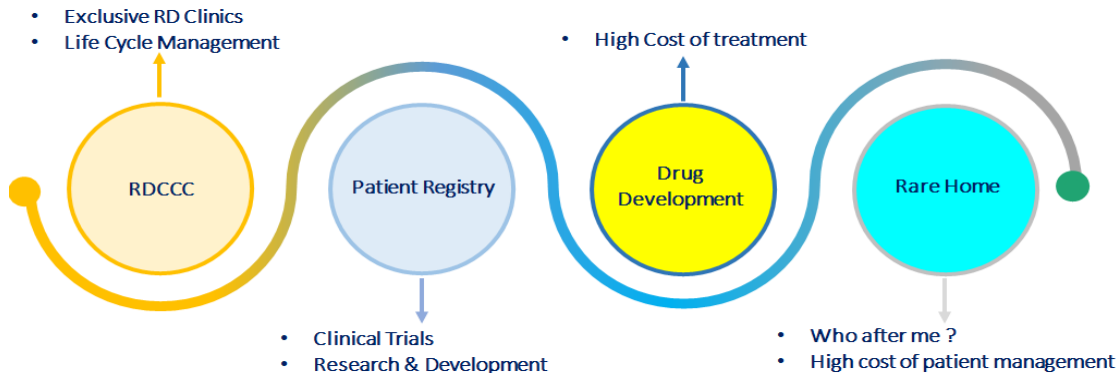




# ORD India & Rare Diseases Torchbearing Journey!



Many a Miles to Go - Many a Milestones to achieve...



# What Can You Do?



Donation to ORDI are exempted under section 80G/5A of Income Tax  
CIT(E)BLR/80G/ N-310/AABCO9919N/ITO(E)-2 Vol 2016-2017

Scan To Donate



**ORDINDIA**

**TAX EXEMPT**

Account Name: Organization for Rare  
Diseases India

Account Number: 918010066683329

Bank: Axis Bank

IFSC Code: UTIB0003449

SWIFT Code: AXISINBB219

Branch: SV ROAD RAM MANDIR,  
MUMBAI - 400104.

PAN: AABCO9919N

Visit  
**[www.ordindia.in](http://www.ordindia.in)**  
to know more!

Or Call, **ORGANIZATION FOR RARE DISEASES INDIA** Helpline - **+91 8892 555 000**

