

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 Indra 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.



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.

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!



The 9th edition of **Racefor7**, conducted in 15 cities on a single day (One Nation One Day, Together for Rare) saw people from across participating in large numbers. With a goal of increasing awareness, it was covered in media (print & digital) & had lot of Social Media posts & shares among people from all walks of life.

The Rare Star Awards

The **Rare Star Awards**, introduced to recognize the exceptional life of Rare Warriors & honour people who have done exceptional work in the field of Rare Disease is one of the first of its kind in India - Introduced on 25th Apr 2024 - on the occasion of “DNA Day” & ORDI’s 10th year anniversary.



REDRESS (Rare Genetic Research Summit)

REDRESS is a two-day summit that brings together researchers, clinicians, industry leaders, and policymakers from across India to discuss the latest advances in Rare Genetic Disease (RGD) research and to develop strategies to improve the lives of patients and their families. The summit features a variety of talks, panel discussions and poster presentations.





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

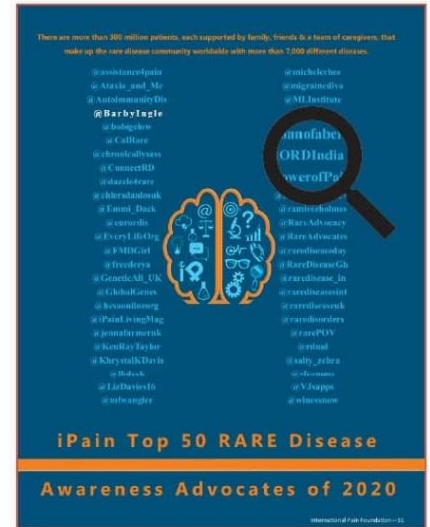
2019-2020 Hindu Changemaker

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 Advoates 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...



It may be rare, but we need to be aware

Join the unique event Race for 7 Seven km walk/run showing your solidarity to Rare Diseases



Main Sponsor IQVIA

ONE NATION ONE DAY, TOGETHER FOR RARE...

"I am honored to support the cause of Rare Diseases and participate in Racefor7. One Nation One Day - Together for Rare. Join me in this multi-city marathon on **Sunday, February 25**, starting at 6:30 am onwards across India. Every step we take brings us closer to raising awareness and finding solutions for our patients with Rare Diseases."

Ramesh Aravind
Actor, Director, TV Presenter

7 km walk/run across 15 cities
Choose the city near you

REGISTER NOW
<https://registration.racefor7.com>

Bengaluru
St. Joseph's Indian School, opp UB City



Main Sponsor IQVIA

ONE NATION ONE DAY, TOGETHER FOR RARE...

"Strength lies in our unity, and hope shines brightest in our collective efforts for rare diseases awareness."

বাড়িমে পাঠ কোমরে হাত
আমি আবার কোমরে হাতকে চাই
বাড়িমে পাঠ কোমরে হাত
আমি আবার কোমরে হাতকে চাই
বাড়িমে পাঠ কোমরে হাত, কোমরে হাত

Anupam Roy
Singer, Music Director, Lyricist

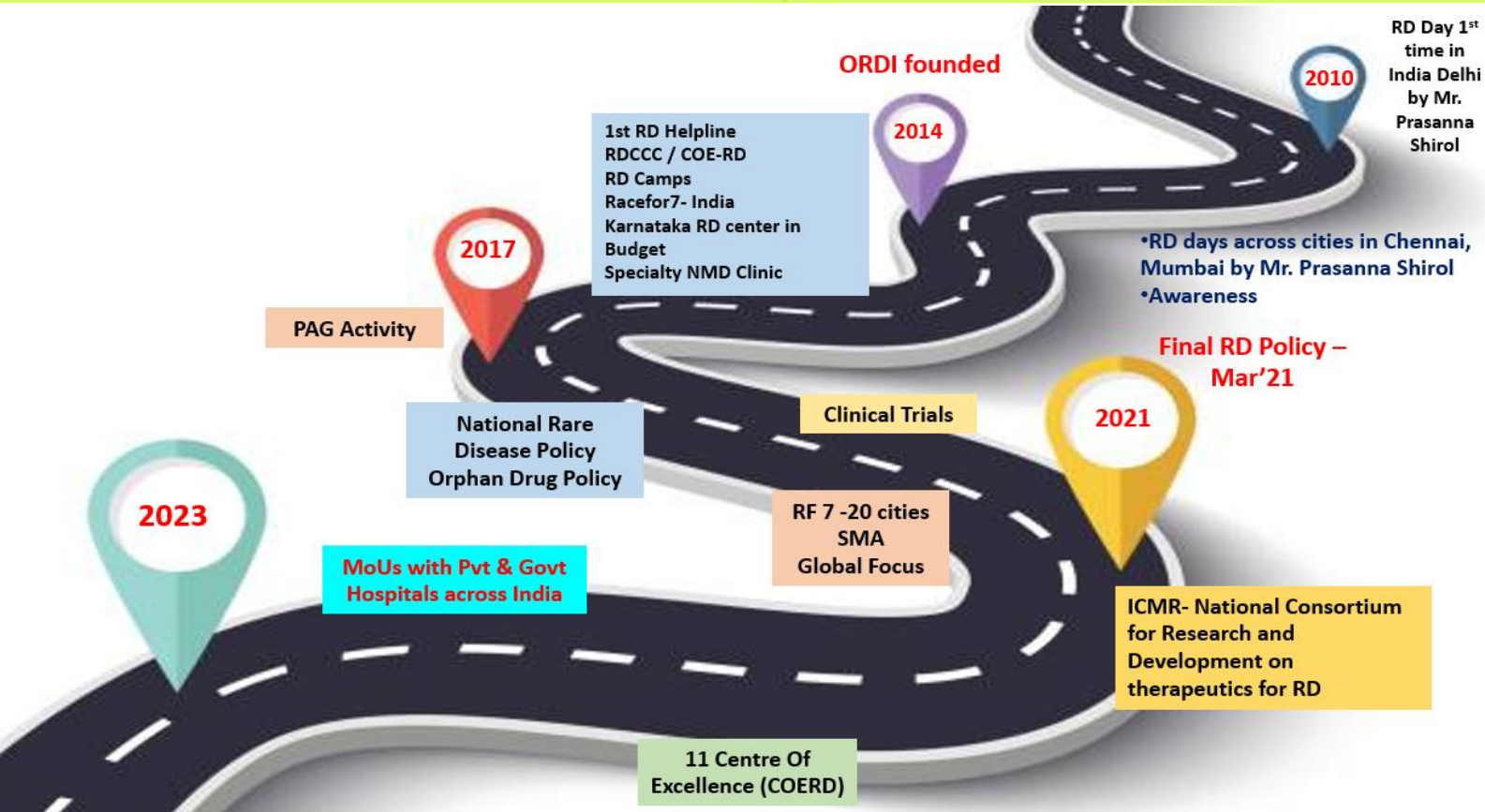
7 km walk/run across 15 cities
Choose the city near you

REGISTER NOW
<https://registration.racefor7.com>

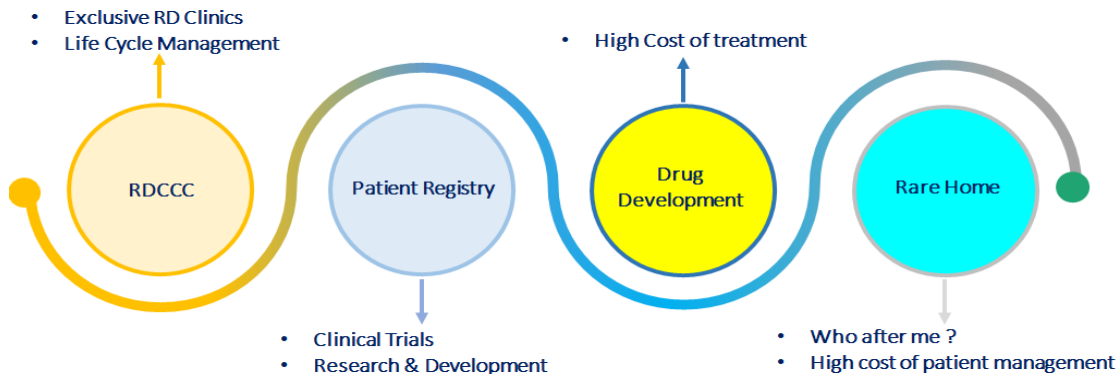
Kolkata
Army briefing ground, Red Road



ORD India & Rare Diseases Torchbearing Journey!



Many Miles to Go - Many 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
to know more!

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

