



ORGANIZATION FOR RARE DISEASES INDIA

Reflecting on Racefor7 Event

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February unfolded as an extraordinary month, marked by the resounding success of the Racefor7 event, where hundreds of volunteers fervently participated in support of rare diseases awareness. In the previous edition of our newsletter, we offered a glimpse into the vibrant scenes from Racefor7 events held in Mumbai, Delhi, Hyderabad, and Bengaluru. This month, we extend our narrative to encompass the spirited manifestations of this event in other cities, encapsulating the spirit of unity and advocacy that reverberated across the nation.

The banner for the Racefor7 event features the text "ONE NATION, ONE DAY, TOGETHER FOR RARE..." in large, bold, orange letters. Below this, it says "Raising awareness and transforming lives" in purple and "25th Feb 2024" in orange. The banner includes logos for the main sponsor IQVIA and other sponsors: Boehringer Ingelheim, AstraZeneca, Roche, novo nordisk, sanofi, and NOVARTIS. On the left, there is a silhouette of a person's head filled with images of diverse children. On the right, there is a map of India with a collage of photos from the event and the Racefor7 logo. The ORDI logo is in the top right corner.

Racefor7 Gallery

Pune



Chennai



Kolkata



Voices of Empowerment: Racefor7 Testimonials

It was an incredible experience to participate in Racefor7 this year, and it was truly an unforgettable one. As someone who has been personally involved in care of patients with rare diseases, this event held a special place in my heart. It was inspiring to see so many individuals from diverse backgrounds come together to support the cause of raising awareness for rare diseases. The energy and enthusiasm at the event was palpable, as participants ran, walked, and cheered their way through the course. But beyond the physical exertion, what truly stood out was the sense of solidarity and community spirit that permeated the atmosphere. Everyone, from participants to volunteers to organizers, was united in a common goal: to make a difference in the lives of those affected by rare diseases. I am happy to have been a part of such a meaningful event, and I look forward to continuing to support the cause in any way I can.

Dr Ashwin Dalal

Head, Diagnostics Division, Centre for DNA Fingerprinting and Diagnostics

“Race or 7 is such a feel-good focus point event that I look forward to every year. As usual this year's event was better than before and brought all the positive sides of all those individuals and families fighting for better care, treatment and rights as citizens of our country for our Rare Disease warriors. It was an amazing event and we had a very well-chosen chief guest in Mr. Ramesh Aravind.”

Dr. Ann Agnes Mathew

Consultant Paediatric Neurologist & Neuromuscular Specialist

Synapse Neuro Centre, Bangalore Baptist Hospital, People Tree Hospitals

“At the outset, allow me, on behalf of the entire Boehringer Ingelheim team, we extend our heartfelt gratitude to you all. Your unwavering commitment to raise awareness across diverse stakeholders for rare diseases in our nation is very commendable. Racefor7 holds immense significance as an initiative dedicated to raising awareness about rare diseases in India. Our collaboration with ORDI in supporting this cause brings us immense satisfaction.

Personally, I am deeply moved by the impact Racefor7 has on our community. Rare diseases often remain hidden in the shadows, affecting countless lives without receiving the attention it deserves. But Racefor7 changes that narrative. It shines a spotlight on the approximately ~7000 rare diseases that exist in our nation, bringing them out of obscurity. Each step at Racefor7 represents hope for earlier diagnosis, better treatments, and improved quality of life for those affected by rare diseases.

Thank you, ORDI, for organizing this impactful event. Let's keep running, raising more awareness and pushing boundaries for a better life for rare disease patients & caregivers.”

Sangita Topiwala

Director – Specialty, Pipeline, Market Access & Patient Engagement, Boehringer Ingelheim India

Celebrating a Decade of Empowerment: ORDI's 10-Year Milestone

In February 2014, a vision was born, igniting a flame of hope and advocacy for rare diseases across India. This year marks a significant milestone as the Organization for Rare Diseases India (ORDI) celebrates a decade of tireless dedication to our rare disease community.

Since our inception, ORDI has been steadfast in our mission to foster inclusivity and support for those affected by rare diseases. Over the past ten years, we have been at the forefront of driving awareness, initiating vital conversations, and catalyzing change to ensure that no one faces the journey of rare diseases alone.

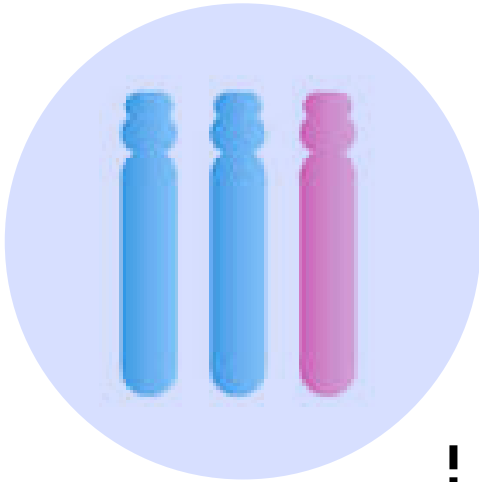
From the early days of grassroots advocacy to the establishment of impactful programs and partnerships, ORDI has consistently strived to make a difference in the lives of individuals and families navigating the challenges of rare diseases. Our initiatives, ranging from awareness campaigns and patient support groups to policy advocacy and international collaborations, have left an enduring mark on the landscape of rare diseases in India. As we commemorate this significant milestone, we extend our heartfelt gratitude to all those who have been part of our journey – our founders, members, volunteers, partners, and the rare disease community at large. It is through your unwavering support, passion, and resilience that ORDI has been able to make a meaningful impact and bring about positive change.

As we look ahead to the future, we reaffirm our commitment to continue advocating for the rights and needs of individuals with rare diseases, striving to create a more inclusive and supportive society for all. Together, let us embark on the next chapter of our journey with renewed vigor and determination, guided by the values of compassion, empathy, and solidarity.

Here's to a decade of dedication, progress, and hope. Happy 10th anniversary, ORDI!



TRISOMY AWARENESS MONTH



Trisomy Awareness Month is observed in March. It's a time dedicated to raising awareness about trisomy, a rare congenital disorder that occurs when an individual has an extra chromosome in some or all of their cells. This extra genetic material can lead to various developmental challenges and health complications.

Trisomy Awareness Month serves as an opportunity to shine a light on this condition, educate communities, and offer support to individuals and families affected by it. Here, we delve deeper into what trisomy is, its types, causes, and the importance of awareness and support.

TRISOMY 13

Perhaps the most well-known form of trisomy, Down syndrome occurs when there is an extra copy of chromosome 21. Individuals with Down syndrome often experience intellectual disabilities, distinctive facial features, and may have certain health issues like heart defects and hearing problems.

TRISOMY 18

This type of trisomy involves an extra chromosome 18. Babies born with Edwards syndrome typically have severe developmental delays, heart defects, and various physical abnormalities. Sadly, many infants with this condition do not survive beyond the first year of life.

TRISOMY 21

Trisomy 13 results from an extra chromosome 13. Like Trisomy 18, Patau syndrome is associated with severe developmental delays and multiple organ abnormalities. Survival beyond infancy is rare for individuals with this condition.

CAUSES OF TRISOMY

Trisomy typically occurs due to errors in cell division during the formation of eggs or sperm, leading to an abnormal number of chromosomes in the resulting embryo. Advanced maternal age is a significant risk factor for trisomy, particularly for Trisomy 21. However, trisomy can occur in pregnancies of any age.

The Importance of Awareness and Support:

Trisomy conditions present unique challenges for individuals and their families. From navigating healthcare systems to accessing appropriate educational resources and support networks, those affected require understanding and assistance. By raising awareness, we foster a more inclusive and supportive environment for individuals living with trisomy and their families.

Trisomy Awareness

1. Educate Yourself:

Take the time to learn about trisomy and its various forms. Understanding the challenges faced by individuals with trisomy can help promote empathy and compassion within our communities.

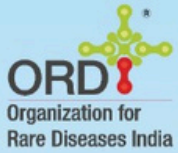
2. Advocate for Inclusivity:

Champion the rights of individuals with trisomy to access education, healthcare, and employment opportunities. By advocating for inclusivity, we work towards a society that embraces diversity and supports all its members.

3. Offer Support:

Whether through volunteering, fundraising, or simply lending a listening ear, your support can make a meaningful difference in the lives of those affected by trisomy. Reach out to local organizations or online communities to find ways to get involved.

Together, let us join hands to raise awareness, promote understanding, and offer support to individuals and families affected by trisomy. By standing together as a community, we can create a brighter and more inclusive future for all.



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