

**THE
RARE
STAR
AWARDS**ORDI
Organization
for Rare Diseases India**AWARDS CEREMONY DNA DAY**

ORGANIZATION FOR RARE DISEASES INDIA

The ORDI Rare Star Awards, a remarkable initiative by the Organization for Rare Diseases India (ORDI), stand as a beacon of recognition and appreciation for outstanding contributions in the rare disease landscape. Launched in conjunction with ORDI's 10th anniversary and coinciding with DNA Day on April 25th, these awards serve as a testament to the dedication and perseverance of individuals and organizations striving to make a difference in the lives of those affected by rare diseases.

The event, held on April 25th, marked a momentous occasion to celebrate these individuals and entities' remarkable achievements. The ORDI Rare Star Awards not only shine a light on the tireless efforts of those working in this often-overlooked field but also serve as a catalyst for greater awareness, support, and collaboration.

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CELEBRATING 10 YEARS OF ORDI WITH RARE STAR AWARDS



ORDI marked a significant milestone on April 25th, 2024, as it celebrated its 10-year anniversary on National DNA Day. The occasion was made even more special with the hosting of the Rare Star Awards, an initiative aimed at recognizing exemplary contributions within the rare disease community.

As we reflect on the success of the event, it becomes evident that the Rare Star Awards encapsulate the spirit of resilience, dedication, and innovation that defines the rare disease community. From individuals who bravely navigate life with a rare condition to researchers and scientists tirelessly pushing the boundaries of knowledge, each awardee represents a beacon of hope and inspiration.

The Rare Star Awards evening highlighted inspiring individuals living with rare diseases, showcasing their resilience and advocacy. Additionally, awards honored genetic counselors, researchers, caregivers, advocacy leaders, and volunteers, emphasizing the collaborative efforts vital for addressing rare disease challenges. The event also recognized innovative startups with the Rare Star – Health Innovation Startup award, reinforcing ORDI's commitment to fostering progress in healthcare solutions for rare diseases.





WINNERS OF RARE STAR AWARDS

Here are the remarkable individuals and organizations who were honored at the Rare Star Awards ceremony for their outstanding contributions to the rare disease community:

1. Lifetime Achievement Category Winner: Dr. Radha Rama Devi



With prestigious accolades and 40 years of pioneering work in Medical Genetics, including establishing India's leading Genetic Diagnostic Service Laboratory and groundbreaking research in Newborn Screening, her impact is truly exceptional. Congrats Dr. Radha Rama Devi!

2. Researcher & Scientist Category Winner: Dr. Mohammed Faruq



As Senior Principal Scientist at CSIR-IGIB, Delhi, with MBBS, PhD (AIIMS Delhi), he led pioneering research in Hereditary Ataxias, showcasing bedside-to-bench excellence over 17 years. Congrats! Dr. Mohammed Faruq!



WINNERS OF RARE STAR AWARDS

3. Role Model Living With Rare Category Winner: Ms. Keya Hathkar



Keya is a nationally acclaimed Author of two best sellers – DANCING ON MY WHEELS & I'M POWERED! She is also an Artist, Coder, Motivational Speaker, YouTuber and Podcaster. Keya has been writing stories to inspire those living with visible and invisible disabilities and spread awareness on rare diseases. Congrats Ms Keya Hathkar

4. Role Model Living With Rare Category Winner: Ms. Kavya Mukhija



Kavya has a Masters in Applied Psychology and works in multiple fields: as a Jon Coach, Creative Writer and Social Media Lead, Content Creator and Ideator. She has been part of many national and international delegations on Disability and Equity. She also has many publications. Congrats Ms. Kavya Mukhija!



WINNERS OF RARE STAR AWARDS

5. Caregiver Category Winner: Mrs. Raghu Bai



Mrs. Raghu Bai is a mother of twin boys diagnosed with Duchenne Muscular Dystrophy (DMD). Both her sons completed BE, lost 1 son in 2016 (22 years) and lose her husband in 2021. Her 25+ years caregiving life illustrates her immense courage, resilience and focus. Congrat Mrs. Raghu Bai!

6. Advocacy Leader Category Winner: Mr. Vikas Bhatia



With 13+ years in Rare Disease Advocacy, he ensures special diet availability for children with Inborn Errors of Metabolism, launching "Diet For Life" and advocating for Rare Disease Policy. Congrats Mr. Vikas Bhatia!



WINNERS OF RARE STAR AWARDS

7. Role Model Category Winner: Dr. Vaibhav Bhandari



Dr. Vaibhav Bhandari has done his PG in Law, Social work and Psychology. He has received Helen Keller Award 2023, Yeshwant Rao Kelkar Youth Award 2023, Honored by the President of India in Dec 2022 with the National Award. Congrats Dr. Vaibhav Bhandari!

8. Volunteer Category Winner: Dr. Saliya S Bawani



With a PhD in Zoology, she has pioneered Parkinson's research and has managed Race For 7 logistics since 2015, showcasing unwavering commitment to community service. Congrats Dr. Saliya S Bawan



WINNERS OF RARE STAR AWARDS

9. Genetic Counselor Category Winner: Dr. Indumathi S N



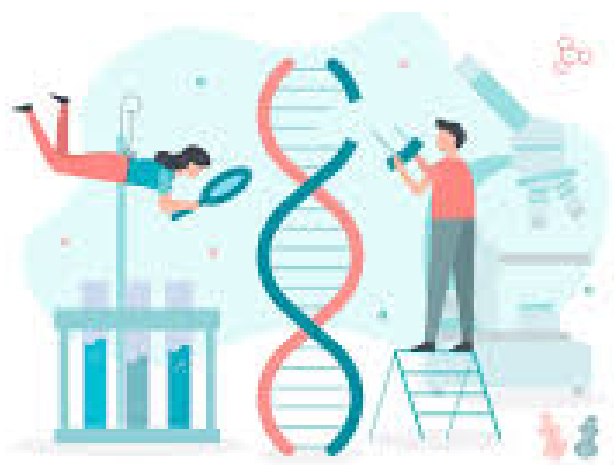
With 13+ years' experience, she's a BGCi-certified level II Counselor, and HoD - Medical Genetics at Apollo Main Hospital, expertly handling 5300+ cases. Congratulations Dr. Indumathi S N!

10. Health Innovation Startup Category Winner: DeepKnomics Labs Pvt Ltd



DeepKnomics™ is a data-driven technology company with a strong vision to build products in clinical diagnostics and immuno-oncology space. DeepDiagnose™ integrates about 75 million associations of standardized symptoms and diseases enabling prediction of rare genetic diseases. Well-deserved recognition for their groundbreaking work!

DECODING LIFE: CELEBRATING THE LEGACY OF DNA DAY



NATIONAL
DNA DAY
25 April

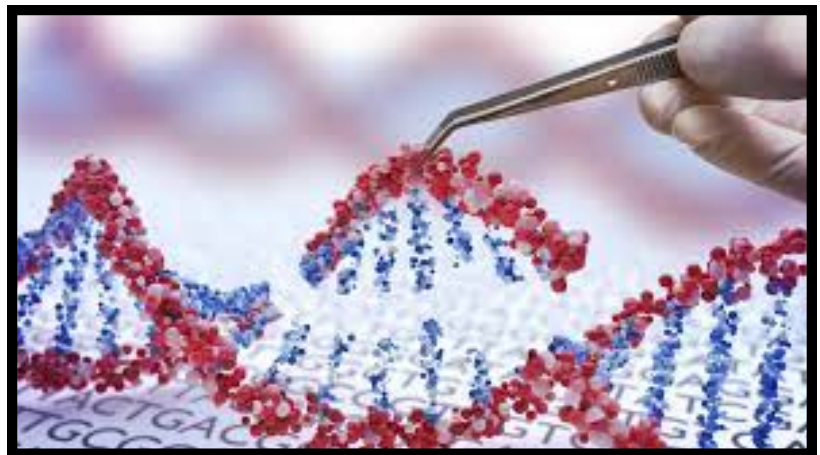
DNA DAY COMMEMORATES TWO LANDMARK EVENTS IN THE FIELD OF GENETICS: THE PUBLICATION OF THE STRUCTURE OF DNA BY JAMES WATSON, FRANCIS CRICK, MAURICE WILKINS, AND ROSALIND FRANKLIN IN 1953, AND THE COMPLETION OF THE HUMAN GENOME PROJECT IN 2003. THESE MILESTONES MARK PIVOTAL MOMENTS IN OUR UNDERSTANDING OF THE BLUEPRINT OF LIFE AND HAVE PAVED THE WAY FOR COUNTLESS DISCOVERIES IN GENETICS AND MEDICINE.

SINCE ITS DISCOVERY IN 1953, THE DOUBLE HELIX STRUCTURE OF DNA HAS BECOME SYNONYMOUS WITH THE ESSENCE OF LIFE ITSELF. EACH YEAR ON APRIL 25TH, SCIENTISTS, EDUCATORS, AND ENTHUSIASTS WORLDWIDE COME TOGETHER TO CELEBRATE DNA DAY, COMMEMORATING THE GROUNDBREAKING DISCOVERY AND THE CONTINUOUS ADVANCEMENTS IN GENETICS AND GENOMICS. IT SERVES AS A RALLYING POINT FOR REFLECTION, INSPIRATION, AND EDUCATION. IT OFFERS AN OPPORTUNITY TO REFLECT ON THE REMARKABLE PROGRESS MADE SINCE THE ELUCIDATION OF THE DNA STRUCTURE, FROM DECODING THE GENETIC BASIS OF HEREDITY TO UNRAVELING THE COMPLEXITIES OF GENE REGULATION AND GENOME FUNCTION. MOREOVER, IT INSPIRES FUTURE GENERATIONS OF SCIENTISTS BY HIGHLIGHTING THE LIMITLESS POSSIBILITIES INHERENT IN THE STUDY OF GENETICS AND GENOMICS. THIS ARTICLE DELVES INTO THE SIGNIFICANCE OF DNA DAY, WE EMBARK ON A JOURNEY THROUGH HISTORY, EXPLORING THE TRANSFORMATIVE IMPACT OF DNA RESEARCH ON SCIENCE AND SOCIETY.

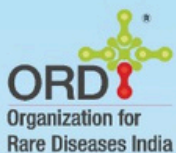
History and Significance:

The completion of the Human Genome Project marked a triumph of collaboration, technology, and perseverance. It not only provided researchers with a wealth of data to explore the genetic basis of health and disease but also catalyzed a revolution in genomic research and personalized medicine. The availability of the human genome sequence has empowered scientists to identify genes implicated in various disorders, develop new diagnostic tests, and discover novel therapeutic targets for treating genetic diseases and cancers. Moreover, the Human Genome Project laid the groundwork for subsequent large-scale genomic initiatives aimed at unraveling the genetic basis of complex traits and diseases. Today, advances in DNA sequencing technology have made it faster, cheaper, and more accessible than ever before to decode the genetic information encoded in our DNA. This has fueled a genomic revolution, with genomics becoming increasingly integrated into biomedical research, clinical practice, and public health initiatives.

**The Evolution of
Personalized
Medicine on DNA
Day:**



DNA Day celebrates the transformative power of genetic testing and personalized medicine, showcasing how understanding our genetic blueprint improves patient outcomes. Genetic testing informs treatment decisions by assessing disease risk, identifying mutations, and guiding medication selection, revolutionizing modern healthcare.



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