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Takeda, UNGCNI initiative strengthens access to rare disease treatment in India

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In November 2021, Takeda Pharmaceutical together with United Nations Global Compact Network of India (UNGCNI) launched a national initiative for improving early access to treatment for Rare Disease Patients in India. The joint rare disease initiative took charge of addressing the challenges to ensure access to treatment for rare disease patients waiting on the crowdfunding portal in an integrated manner. Through the initiative, 300+ PSUs and corporate leaders were reached, which has helped to generate a pool of insights and recommendations that will help in shaping the future of access to rare disease treatment in the country.

The six-month intensive initiative has been able to bring together stakeholder groups (private sector, PSUs, corporate giants, etc.) that can support mobilising and operationalising funding for the rare disease under CSR grants and donations for strengthening the existing crowdfunding mechanism and pathways set in the India Rare Disease Policy.

Furthermore, it has created the roadmap for addressing rare disease funding requirements in alignment with the Government policies and guidelines Ministry of Corporate Affairs, Department of Public Enterprises, and Ministry of Health and Family Welfare, Govt of India.

The eminent experts from public and private sector organisations that participated in the initiatives include MoH&FW, AIIMS (New Delhi), Kerala State Legal Services Authority (KELSA), CoEs (SGPGI, Lucknow, KEM, Mumbai, SSKM, Kolkata), and 24 PSUs and Corporate Leaders (e.g., BHEL, Bharat Petroleum, ONGC etc).