RDI Strategic Framework 2026 – 2030

RARE DISEASES INTERNATIONAL

OUR VISION	A world where people living with rare conditions* and their families are fully recognized, supported and empowered in all aspects of life.						
OUR MISSION	To be the global advocacy leader and connector advancing equitable and inclusive outcomes for people living with rare conditions and their families worldwide.						
OUR VALUES	EQUITABLE We strive for fair access, opportunities, and outcomes for people living with rare conditions everywhere.	INCLUSIVE We value inclusion and reflect the diversity of our community, ensuring meaningful engagement of all voices.	COMMUNITY-CENTERED The interests and needs of the rare community are at the heart of everything we do.	TRANSPARENT We act with integrity, openness, and accountability in all our relationships and decisions.	INDEPENDENT We maintain autonomy and objectivity to represent the rare community credibly and responsibly.	COLLABORATIVE We work across sectors and regions, connecting diverse stakeholders to achieve shared impact.	INNOVATIVE We are forward-looking and embrace innovation to the benefit of the entire rare community.
OUR STRATEGIC GOALS	*ENGAGE* GLOBAL RARE COMMUNITY Connect & strengthen the global rare community	*BUILD* CAPACITY OF THE RARE COMMUNITY Upskilling our members at the global and regional level	*LEAD* GLOBAL AWARENESS & ADVOCACY Represent our members globally to influence awareness & policy	*ADVANCE* IMPROVEMENTS IN DIAGNOSIS, TREATMENT & CARE Develop standards, publish position statements, and define best practices			
OUR STRATEGIC PRIORITIES**	• Foster connections in the rare community • Bring our members together • Support a global network for rare conditions • Enable best practice sharing	• Provide trainings, education and support to strengthen the rare community • Support network development in our regions • Promote leadership continuity and evolution • Nurture young leaders	• Raise awareness and knowledge on rare conditions • Engage with WHO and UN institutions, promoting their resolutions • Facilitate GAPRD development & implementation • Advocate for regulatory harmonization and innovative funding models	• Advance equitable access to diagnosis, treatment and care • Promote integrated care models • Promote development of and participation in RD registries • Support efforts to map and measure rare conditions globally			
OUR STRATEGIC ENABLERS	STAKEHOLDER ECOSYSTEM HEALTH Reinforce legitimacy, independence, and influence through a trusted and engaged stakeholder network.	FINANCIAL RESILIENCE Strengthen our diversified and sustainable funding model to enable continued strategic flexibility and operational impact.	ORGANISATIONAL INTEGRITY Ensure strong governance, aligned leadership, and a cohesive culture to sustain credibility and institutional strength.	OPERATIONAL EXCELLENCE Leverage technology, optimize structures, processes, and resources allocation to ensure measurable impact.	PEOPLE DEVELOPMENT Hire, develop and retain a high-performing and diverse team with the capabilities and culture to deliver on our mission.		

*** Note:** In this document, "rare conditions" serves as an umbrella term for **people living with rare diseases, disorders, conditions, and syndromes, both diagnosed and undiagnosed**.

** To be reviewed and refined by the organization to unsure full alignment with current and planned projects and initiatives.