

<p>10:10- 11:30</p>	<p><b>PLENARY SESSION</b></p> <p><i>Speakers:</i>  <b>Alena Alexandrovna Yartseva (Kuratova)</b>, CEO of the “Rare Women”  <b>Alexander Evgenievich Tkachenko</b>, Chairman of the Board of the Presidential Foundation “Circle of Kindness”  <b>Vasily Gennadievich Ignatiev</b>, CEO of R-Pharm Group</p>		
<p>11:30- 12:00</p>	<p>Coffee break</p>		
<p>12:00- 13:30</p>	<p><b>A SHARED ARCHITECTURE OF CARE</b></p> <ol style="list-style-type: none"> <li>1. Rare diseases as an area of state responsibility</li> <li>2. National policy models in the field of rare diseases</li> <li>3. Access to orphan drugs: economics and solutions</li> <li>4. Patient organizations as partners of the state</li> </ol> <p><i>Moderator:</i>  <b>Oksana Gorchakova</b>          Director of the Center for the Development of International Socio-Cultural and Business Relations “Bridges”, ICF-certified coach, lecturer in Indian philosophy</p> <p><i>Speakers:</i>  <b>Nada Alfy Thabet</b> (Egypt)          Nobel Peace Prize nominee; Member of the Egyptian House of Representatives; Member of the Supreme Advisory Committee on the Rights of Persons with Disabilities; Founder of the “Village of Hope”</p> <p><b>Sheela Upadhyaya</b> (United Kingdom)          Senior Advisor in the Healthcare Practice at FIPRA International; Member of the Board of the World Orphan Drug Congress</p> <p><b>Prasanna Shirol</b> (India)          Co-founder and Executive Director of ORDI (Organization for Rare Diseases India)</p> <p><b>Bithika Ghosh</b> (India)          Secretary of the Muscular Dystrophy Patients’ Welfare Society; initiator of the state project “Rare Disease Clinics”</p>	<p><b>VITALITY, RESILIENCE, ALERTNESS</b></p> <ol style="list-style-type: none"> <li>1. Rare diseases as a domain of state responsibility</li> <li>2. National policy models in the field of rare diseases</li> <li>3. Access to orphan drugs: economics and decision-making</li> <li>4. Patient organizations as partners of the state</li> </ol> <p><i>Speaker:</i>  <b>Alena Yartseva</b> (Kuratova), CEO of the “Rare Women”</p>	<p><b>VITALITY AS THE FOUNDATION OF LEADERSHIP</b></p> <ol style="list-style-type: none"> <li>1. From Parental Initiative to Professional Institutions</li> <li>2. Patient NGOs as Partners in Healthcare Systems</li> <li>3. International Cooperation and Global Networks</li> <li>4. Women’s Leadership in the Patient Movement</li> </ol> <p><i>Moderator:</i>  <b>Elena Belonogova de Torrejon</b> (Russia, United Kingdom)          Consulting physician at DEBRA Russia; pediatrician, dietitian, and pediatric neurologist</p> <p><i>Speakers:</i>  <b>Deniz Yilmaz Atakay</b> (Turkey)          Founder of the first PKU Families Association in Türkiye; delegate of the European PKU Association; founding member of GAP</p> <p><b>Hanaa El-Sadat</b> (Egypt)          Founder of the Yasmine El Samra Foundation – DEBRA Egypt; Member of the Executive Committee of DEBRA International</p> <p><b>Angélique Sauvestre</b> (France)          President of DEBRA France; Vice President of DEBRA International</p> <p><b>Parvathy Krishnan</b> (USA)          President of the Parvathy Krishnan Family Foundation</p>
<p>13:30- 14:30</p>	<p>Lunch</p>		

14:30-  
16:00

### VITALITY AS INFLUENCE

1. From Initiative to System
2. Inclusion as a New Social Norm
3. Partnership as a Model for the Future
4. The Global Rare Disease Agenda

**Moderator:**

**Victoria Polenova** (Russia)  
President of MARZ; Head of Scientific Projects Development at DEBRA Russia

**Speakers:**

**Dr. Durhane Wong-Rieger** (Canada)  
President of the Canadian Organization for Rare Disorders

**Ravdeep Singh Anand** (India)  
Founder and President of the Dystrophy Annihilation Research Trust (DART)

**Nadiyah Hanim Abdul Latif** (Malaysia)  
President of the Malaysian Rare Disorders Society (MRDS)

**Anastasia Cherepanova** (Russia)  
Director of the charitable foundation "Life as a Miracle"

### A VITAL WOMAN AS A FAMILY'S MEDICAL RESOURCE

1. The Mother as a Partner in Care, Not an "Invisible Resource"
2. The Diagnostic Journey: From System Gaps to System Solutions
3. Care Without Self-Destruction: Redistributing Responsibility Within the Family
4. Home Care as an Infrastructure of Family Resilience

**Moderator:**

**Elena Belonogova de Torrejon** (Russia, United Kingdom)  
Consulting physician at DEBRA Russia; pediatrician, dietitian, and pediatric neurologist

**Speakers:**

**Dr. Gayatri Rangarajan Iyer** (India)  
PhD; Tata Institute for Genetics and Society; Certified Genetic Counselor, Level II

**Sushma Gopalan** (India)  
Clinical Psychologist, PhD; Head of Child Life Services at Manipal Hospital; Founder of the Kridavat Child Life and Beyond Center

**Mercedes Alessandri** (Chile)  
Coordinator of the DEBRA Chile Home Nursing Care Program

**Dr. Omar Jagne** (Gambia)  
CEO of the Africmed International Hospital Network; Chair of the Medical and Anti-Doping Committee of the National Olympic Committee of The Gambia

### VITALITY AS A CHOICE

1. Stigma, guilt, and cultural pressure
2. From personal tragedy to leadership
3. Living with uncertainty
4. The hero's journey: the courage of everyday life

**Moderator:**

**Olga Gremyakova** (Russia)  
Founder of the Gordey Foundation

**Speakers:**

**Catherine Jayasuriya** (USA)  
Founder and Executive Director of Coalition Duchenne; filmmaker and producer

**Vlasta Zmazek** (Croatia)  
President of DEBRA Croatia; Member of the Executive Committee of DEBRA International; Member of the Board of Directors of RareResourceNet

**Clair Malik** (Egypt)  
Founder and Head of the Institute for People with Hearing Impairments at the Anglican Church in Cairo

**Anastasia Sherikhora** (Russia)  
Board Member of the NGO "In One Breath"; Founder of the CF Kids online resource for parents of children with cystic fibrosis; translator and intercultural communication specialist; interpreter-guide

16:00-  
16:15

break



16:15-  
17:45

## MAN'S HAND

1. A man in the context of a rare diagnosis: from reaction to action
2. A man as a pillar of the system: life alongside a "rare woman"
3. A rare woman through her son's eyes: how the perception of family is formed
4. A man through children's eyes: the father's role in family resilience

**Moderator:**  
**Sergey Nasibyan** — psychologist, trainer, consultant

**Speakers:**  
**Ravdeep Singh Anand** (India)  
Founder and President of the Dystrophy Annihilation Research Trust (DART)

**Igor Chuvstvinov** (Russia)  
Commercial Practice Lawyer at Nevsky IP Law; Patent Attorney; Lecturer and Researcher at the Department of Intellectual Property Law, Kutafin Moscow State Law University (MSAL)

**Ivan Kuratov**  
11th-grade student, rare women son

**Dr. Omar Jagne** (Gambia)  
CEO of the Afrimed International Hospital Network; Chair of the Medical and Anti-Doping Committee of the National Olympic Committee of The Gambia

## VITALITY AND CREATION

1. From personal experience to a social movement
2. Community as a source of strength
3. From accepting the diagnosis to seeking solutions
4. Personal experience as a social resource

**Moderator:**  
**Olga Gremyakova** (Russia)  
Founder of the Gordey Foundation

**Speakers:**  
**Sofia Pesochinskaya** (USA)  
Founder of the Vera Pesochinskaya Research Foundation; participant of NTSAD

**Shikha Metharamani** (India)  
President and Founder of the Indian Prader-Willi Syndrome Association (IPWSA)

**Shruti Gupta** (India)  
Founder of LAMA2 India

**Priscilla Vicent Chassama** (Tanzania)  
Chair of the Tanzania Sickle Cell Warriors Organisation (TASIWA)

## SEPARATION OF THE DIAGNOSIS FROM THE IDENTITY

1. From patient to subject of one's own life
2. Stigma, guilt, and social isolation
3. Community as a space of strength
4. The voice of women with a diagnosis in the global movement

**Moderator:**  
**Roza Mamleeva** (Russia)  
Public speaking and systems thinking coach; certified finisher of the Bosphorus Cross-Continental Swimming Race

**Speakers:**  
**Natalia Skrebtsova** (Russia)  
Executive Director of the "Butterfly Children" Foundation

**Toni Roberts** (South Africa)  
Co-founder of DEBRA South Africa

**Setsuko Shiraishi** (Mexico)  
President of DEBRA Mexico and Member of the Executive Committee of DEBRA International

**Veronika Volokha** (Russia)  
Chair of the Khabarovsk District Local Organization of the All-Russian Society of Persons with Disabilities (VOI); organizer of adaptive cultural and social events for people with disabilities

18:00

Forum Closing