Report from the inauguration of the

NGO COMMITTEE FOR RARE DISEASES
This event took place under the patronage of:

Queen Silvia of Sweden

And

The Conference of NGOs in Consultative Relationship with the United Nations (CoNGO)

at the United Nations Headquarters, New York

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With the support of

The Government of the Kingdom of Belgium
The Government of the Republic of France
The Government of the Republic of Malta
The Permanent Mission of Estonia to the United Nations &
The Swedish Ministry of Health and Social Affairs

The launch of the NGO Committee for Rare Diseases was also endorsed by a number of personalities through statements of support:

Baroness Jane Campbell – Independent
Member of the UK House of Lords


Françoise Grossetête – Member of the European Parliament and Vice-Chair of the Group of the European People’s Party

President Tarja Halonen – Former President of Finland and Co-Chair of the WHO-OHCHR High Level Working Group for the Health and Human Rights of Women, Children and Adolescents

Federico Mayor Zaragoza – President of the Foundation Culture of Peace and Former Director-General of UNESCO (1987 – 1999)

Marek Plura – Member of the European Parliament

Dainius Puras – United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

Miklós Szócska – Former Minister of State for Health of Hungary, Director of the Health Services Management Training Centre of the Budapest Semmelweis University
The NGO Committee for Rare Diseases is a substantive committee established under the umbrella of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO). Its goal is to promote rare diseases as a priority in global health, research, and social and medical care as part of the UN 2030 Agenda: the Sustainable Development Goals (SDGs). This Committee is an initiative of the Ågrenska Foundation and EURORDIS-Rare Diseases Europe in cooperation with Rare Diseases International (RDI).

The launch of the NGO Committee for Rare Diseases took place on 11 November 2016 at the United Nations headquarters in New York under the patronage of her majesty Queen Silvia of Sweden, with the active support and encouragement of several governments and with the engaged participation of a broad range of civil society actors.

This ‘Global Gathering for Rare Diseases’ brought together in New York 100 participants from around the world, and more than 1,600 people connected to the live webcast through the Committee’s dedicated website.

Participants

<table>
<thead>
<tr>
<th>Rare Disease Community</th>
<th>United Nations Bodies</th>
<th>National Governments</th>
<th>Academia and Research</th>
<th>Pharmaceutical Industry</th>
<th>Other Civil Society Organisations</th>
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</table>

Participants by country of origin

People from all continents signed up to the event, making it a truly global gathering.
There are over 6,000 identified rare diseases. Even though one disease may be rare, the number of people affected by rare diseases is huge. There is an estimated 30 million affected people in Europe alone, and an estimated 350 million affected individuals worldwide.

One of the main objectives of the inauguration of the NGO Committee for Rare Diseases was to establish rare diseases as a global health priority for the participants in the room and the audience watching the live stream online.

The testimonials from persons living with a rare disease and advocates during the meeting served to illustrate that rare diseases impact not only a person’s health, but also issues around their socio-economic status, family, education and labour. Difficulties such as poverty, unemployment, stigmatisation and social exclusion are not distant concepts for people living with a rare disease. They are in fact a daily reality, and a direct consequence of their disease.

Gender is an extra layer of complexity – women and girls with rare diseases and their mothers, often suffer from multiple exclusions from health care systems, labour markets and so on.

As the struggles faced by people living with a rare disease are shared across many different diseases and geographies, these common challenges demand common solutions.

During panel one, a number of representatives from the rare disease community presented their strategies and vision for tackling rare diseases. The overwhelming message that came out of this session was that differences in values and priorities are not an obstacle to working together. In fact, this complexity and diversity can be turned into an advantage for impactful action from the grassroots to the global level.

From left to right, Yann Le Cam (EURORDIS), Abbey Meyers (NORD), Anders Olason (Ågrenska), Avril Daly (Retina International) and Terkel Andersen (EURORDIS)
An international rare diseases community is emerging, increasingly organised to take global action. A number of initiatives in various fields were presented at the meeting:

» The International Rare Diseases Research Consortium (IRDiRC) is paving the way for future cures and treatments through the creation of a platform for cooperation in scientific research.

» The International Federation of Pharmaceutical Manufacturers and Associations (IFPMA) is committed to finding solutions for rare diseases through the development of orphan medicinal products and has founded a Rare Diseases Working Group gathering 14 leading international pharmaceutical manufacturers.

» OrphaNet has evolved into the primary international portal of reference for the inventory and classification of rare diseases.

» The International Conference on Rare Diseases and Orphan Drugs (ICORD) has become the annual gathering point for rare diseases stakeholders, and is playing today a central role in advancing knowledge, research, care, information and education about rare diseases globally.

The last few decades have been characterised by the expansion of networks of patient and disability organisations. The testimonials from the ten representatives of the rare disease community during session six of Panel one indicated this growing trend towards global collaboration. Patient and disability organisations have

To have access is not enough. Only through strong social policies can human rights be made usable for people, and the potential of people with rare diseases to contribute to society be fulfilled. NGOs have the power, the knowledge, the energy and ability needed to achieve that goal

Daniela Bas, Director, Division for Social Policy and Development (DSPD), UN Department of Economic and Social Affairs (DESA)
played an essential role in breaking the isolation of persons with a rare disease transforming individual stories into collective action and fostering exchange. These organisations have been the true pioneers in the advancement of rare disease national strategies and the establishment of legal frameworks like the US Orphan Drug Act and the EU Orphan Medicinal Products Regulation.

As these networks of patient and disability organisations grow and in turn foster horizontal collaboration with other stakeholders, the need for a global platform increases. A platform that serves as a space to share ideas but also to bring these ideas to the leading force of global collaboration: the United Nations. This is the role of the NGO Committee for Rare Diseases.

As one of the forty substantive Committees of the Conference of NGOs in Consultative Relationship with the United Nations (CoNGO), the NGO Committee is now an integral part of the principal interface between the world’s NGOs and the United Nations system. It is through the input and expertise of NGOs that national governments and United Nations agencies can improve their output and generate policies that truly respond to needs at the grassroots level. By having a seat at the table, the NGO Committee for Rare Diseases can now empower its local members, providing the link between the bottom-up and the top-down approach and formalising alliances.

Its main mission is thus to:

» Bring visibility and understanding about rare diseases to the United Nations.

» Act as an advocacy platform for the issue of rare diseases, creating a space for collaboration.

» Collect and share accurate information about rare diseases and associated challenges.

» Elevate rare diseases as a priority within global public health, research, medical care, social care and social integration.

Our experience in hemophilia shows how the support of the United Nations can help make a difference to reduce stigma, gain support from governments and encourage better regulatory cooperation »

Alain Weill, President of the Board, World Federation of Hemophilia (WFH)
Rare diseases are relevant to the Sustainable Development Goals of the UN 2030 Agenda

The timing of the new NGO Committee for Rare Diseases is perfectly aligned with the kick-off of the United Nations 2030 Agenda: the Sustainable Development Goals (SDGs). This universal agenda is comprised of 17 goals, a number of which are in synergy with the goals of the rare disease community.

As Navid Hanif, Director of the Office for ECOSOC Support and Coordination, said during the meeting: ‘Development is a mirage without health’. The UN Millennium Development Goals (2000-2015) already included three health-specific targets and paved the way for future international collaboration. However, these goals were narrow in scope and did not highlight the connection that health has with so many other aspects (e.g. economic development, social integration, gender issues and education).

The coherence between the rare diseases community’s goals and the SDGs was confirmed by members of United Nations agencies at the inauguration. The bearing principle of the Agenda, “Leave no one behind”, which should be upheld throughout the implementation, was mentioned by several speakers. Vidhya Ganesh of UNICEF said that although the prioritisation of rare diseases would be challenging as part of the operational work of the agency, they would support it in their advocacy efforts to ensure that their mandate is fulfilled and that ‘no child is left behind’.

Similarly, Nata Menabde, Executive Director of the World Health Organisation Office at the United Nations, said that the WHO was pushing for a new agenda, transforming itself into a more collaborative partner and focusing on the goal of universal health coverage. In words that echoed those of UNDP Director Helen Clark at the 11th ICORD meeting, Nata Menabde said: ‘If we are serious about leaving no one behind, then we cannot leave behind people who have rare diseases just because they are few’. She declared the openness of the WHO to collaborate with the NGO Committee in the future.

The Sustainable Development Goals are inclusive. If they are not met for everyone equally, then they are not met »

Lauren Barredo, Manager, Thematic Group on Health, UN Sustainable Development Solutions Network (SDSN)
The overall outcome of Panel two was the need to take a rights approach, where persons with rare diseases need to be seen as more than just patients or their disease, but as human beings with rights to health and well-being. As Tenu Avafia, Policy Adviser on HIV, Health and Development Practice at the United Nations Development Programme (UNDP) said in his concluding note ‘this must be framed around the chapeau of human rights as they are enshrined in most countries’ constitutions’.

People living with a rare disease must be given the chance to fulfil social functions and contribute to a common welfare. As Marek Plura, Member of the European Parliament, said: ‘it is not possible to misuse the potential of citizens’. In line with this view, Daniela Bas, Director of the Division for Social Policy and Development (DSPD) advocated for the need to move from a medical model to a social model. In conclusion, a place at the table for rare diseases was confirmed and a number of potential initiatives proposed.

If we are serious about leaving no one behind, then we cannot leave behind people who have rare diseases just because they are few”

Nata Menabde, World Health Organisation (WHO)
A call for global action on rare diseases to achieve the 2030 Agenda

The 17 SDGs will not be achieved without the activism of civil society. Navid Hanif, Director of the Office for ECOSOC Support and Coordination, pointed out that while governments implement policy, they more often than not need the guidance, expertise and real-life evidence coming from patient organisations and NGOs to produce sound policies. For rare diseases, the most important role for these groups is two-fold:

» to press on governments to include rare diseases in their policies and in their budgets; and
» to take a system-strengthening approach by advocating to the global community as a whole on the issues people living with a rare disease face.

A key success factor for the creation of this enabling environment is alignment between stakeholders. Several members of UN agencies gave examples of success stories coming from the common engagement of NGOs, particularly in the field of health. For instance, non-communicable diseases were put to the fore following a six-year campaign and are now integral to all United Nations agencies’ programmes. Similarly, the International Diabetes Federation (IDF) led a campaign in 2006 and secured a UN resolution (61/225) after six months only, affirming diabetes as a major global health threat. In the case of rare diseases, Malta Ambassador, H.E. Carmelo Inguanez, welcomed the use of a UN resolution as a tool to encourage further action worldwide.

In order to do this, there are various fora and initiatives available to rare disease NGOs that are in consultative relationship with the United Nations, including those groups that are members of the NGO Committee for Rare Diseases:

» The High-Level Political Forum (HLPF): this is United Nations’ central platform for the follow-up and review of the 2030 Agenda for Sustainable Development and the SDGs. The HLPF includes voluntary country reviews, thematic reviews on progress of SDGs as well as a range of side events that can be organised by major stakeholders like civil society.

» ECOSOC Partnerships Forum: Every year ECOSOC and other UN entities collaborate to bring together leaders from government, the private and non-profit sectors and civil society to discuss multi-stakeholder partnerships.

» The World Health Assembly: This is the decision-making body of the WHO and determines the policies of the organisation, appoints the Director-General and approves the proposed programme budget. There are also a number of side-events organised on the same days.

» Official International days: These can be a good opportunity for strong communication and advocacy campaigns such as Official WHO health days.

» The Commission for Social Development (CSocD): This is the key UN body advising ECOSOC on social policies of a general character and, in particular, on all matters in the social field not covered by the specialised inter-governmental agencies.

» The UN Convention on the Rights of People with Disabilities (CRPD): This is intended as a human rights instrument with an explicit social development dimension. As it adopts a broad categorization of persons with disabilities it is possible for the rare diseases community to employ this instrument in its advocacy where relevant and hold accountable those countries that are signatories.

Hawa Dramé, Founder of Fondation Internationale Tierno et Meriam (FITIMA) and Ramaiah Muthyala, Founder of the Indian Organization for Rare Diseases (IORD)

I truly believe that the time for rare diseases is now and we stand committed to assist in any way we can at UNDP

Tenu Awafo, Human Rights, Law and Treatment Access, HIV, Health and Development Group, United Nations Development Programme (UNDP)
UN General Assembly Resolutions: These are voted on by all member states of the UN in the General Assembly. They usually require a simple majority to pass. These are generally non-binding towards member states but they may act as soft law. Rare Diseases advocates can try to collaborate with governments to push for a resolution on Rare Diseases (particularly on Rare Disease Day as it was done for Diabetes).

The opportunities for global action and global advocacy can be facilitated through closer collaboration with UN agencies and the introduction of rare diseases into their own programmes and advocacy.

The end of the inauguration saw the presentation of the NGO Committee Founding Act, demonstrating the consensus of event participants that rare diseases are a global healthy priority.

I am moved by what I have heard today - testimonies of great breadth and depth, from all corners of the globe, from people whose knowledge is grounded in daily - and often dramatic - reality.

Cyril Ritchie, President of CoNGO 2011-2018
The synergies between the UN Sustainable Development Goals and rare diseases

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<tr>
<th>Sustainable Development Goals</th>
<th>Rare Disease Challenges</th>
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<tr>
<td><strong>Goal 1</strong> End Poverty in all its forms everywhere</td>
<td>Persons with rare diseases are often trapped in a vicious cycle of vulnerability and poverty due to exclusion from health care and education systems, as well as job markets</td>
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<td><strong>Goal 3</strong> Ensure healthy lives and promote well-being for all at all ages</td>
<td>Achieving universal health coverage implies attending to the needs of persons living with a rare disease who need more and better medicines, appropriate diagnosis and lifelong care and social support</td>
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<td><strong>Goal 4</strong> Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all</td>
<td>50% of rare diseases affect children who often face difficulties attending school due to inaccessibility of facilities and non-adapted teaching methods</td>
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<td><strong>Goal 5</strong> Achieve gender equality and empower all women and girls</td>
<td>Recognising and valuing unpaid care and domestic work that many mothers of children (including when they are grown adults) with rare diseases take on will be a step towards greater gender equality</td>
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Inauguration Programme

**KEYNOTE ADDRESSES**

10:00-11:00

1. The United Nations and Civil Society: CoNGO and CoNGO Committees
   Mr Cyril Ritchie, President of CoNGO 2011-2018

2. Public Health in the Mandate of the United Nations Economic and Social Council
   Mr Navid Hanif, Director, Office for ECOSOC Support and Coordination, UN Department of Economic and Social Affairs (DESA)

3. Rare Diseases: A Common Cause at the Global Level
   Mr Anders Olason, Chairman, Ågrenska

4. How It All Started: The Contribution of the NGO Community to Advancing the Cause of Rare Diseases
   Ms Abbey S. Meyers, President Emeritus, National Organization for Rare Disorders (NORD)
   Mr Terkel Andersen, President of the Board of Officers, EURORDIS-Rare Diseases Europe, Chairman of the Board, Danish Hemophilia Society

**PANEL DEBATE 1**

11:00-13:30

**THE GLOBAL STATE OF PLAY OF RARE DISEASES**
Moderator: Mr Yann Le Cam, Chief Executive, EURORDIS-Rare Diseases Europe; Council Member, Rare Diseases International (RDI)

5. A Call for Global Action Coming from Civil Society
   Mr Yann Le Cam, Chief Executive, EURORDIS-Rare Diseases Europe, Council Member, Rare Diseases International (RDI)

6. Tackling Rare Diseases Internationally Through National and Regional Strategies
   Europe » Ms Avril Daly, Vice-President of the Board of Officers, EURORDIS-Rare Diseases Europe; Chief Executive, Retina International
   North America » Mr Paul Melmeyer, Associate Director of Public Policy, National Organization for Rare Disorders (NORD)
   Latin America » Ms Migdalicia Denis, Founder, Venezuelan Society for Pulmonary Hypertension; Governing Board Member, International Alliance of Patients’ Organisations (IAPO)
   Russia » Ms Irina V. Myasnikova, President, Interregional Public Organisation « Help for Patients with Cystic Fibrosis », Co-Chair, All-Russia Patients Union
   Middle East and Central Asia » Mr Sirous Eftekhari, International Affairs, Rare Diseases Foundation of Iran (RADOIR)
   Africa » Ms Hawa Dramé, Founder, Fondation International Tierno et Mariam (FITIMA), Burkina Faso and Guinea
   Japan » Ms Yukiko Nishimura, President, ASrid (Japanese Advocacy Service for Rare and Intractable Diseases)
   China » Ms Rachel Yang, Director of International Affairs, Chinese Organization for Rare Disorders (CORD)
   Malaysia » Ms Lee Yee Seng, President, Malaysia Lysosomal Diseases Association
   Australia » Ms Megan Fookes, Founder, Rare Voices Australia; Council Member, Rare Diseases International
   in conversation with Ms Vidhya Ganesh, Deputy Director, Programme Division, United Nations Children’s Fund (UNICEF)
Goal 8  Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all  Persons with rare diseases and disabilities are often marginalised from job markets due to a lack of accessible facilities, flexible working hours and adapted roles.

Goal 9  Build resilient infrastructure, promote inclusive and sustainable industrialization and foster innovation  There is a need to invest in research and development of therapies, health technologies and diagnostic tools for persons with rare diseases. Accessibility to infrastructure is key for persons with rare diseases in order to be included in society.

Goal 10  Reduce inequality within and among countries  People living with a rare disease tend to remain a marginalised and invisible population suffering from discrimination in the health, labour and governance fields.

Goal 17  Revitalise the global partnership for sustainable development  The rare disease community is increasingly interconnected, with a myriad of networks of patient advocates, regulators, research and industry. The NGO Committee for Rare Diseases embodies this goal as multi-stakeholder partnerships are enshrined in its by-laws.
The organisers of the inauguration of the NGO Committee for Rare Diseases would like to give their special thanks to:

Ted FitzGerald  
Director of Global Research Services, FHI 360

John Forman  
Past-President, International Conference on Rare Diseases and Orphan Drugs (ICORD)

Megan Fookes  
Co-Founder, Rare Voices Australia

Michele Galen  
Independent strategic advisor

Vidhya Ganesh  
Deputy Director of Programme Division, UNICEF

Jean-Pierre Gaspard  
Chief Executive, AFM-Telethon

Gustavo Gonzalez-Canali  
Senior Advisor at UN Coordination Division, UN Women

Jaimie Grant  
Communications Officer, International Disability Alliance

Steve Groft  
Senior Advisor to Director, NCATS/NIH/USA

Rae Gurewitsch  
On site UN Representative, Hadassah

Navid Hanif  
Director of Office for ECOSOC Support and Coordination, United Nations Department of Economic and Social Affairs (DESA)

Marc Hanauer  
Deputy director, INSERM OrphaNet

Matthew Harold  
International Public Affairs Lead for Rare Disease, Pfizer, Inc.

Robert Hejdenberg  
President, Agrenska

Anja Helm  
Manager of Relations with Patient Organisations, EURORDIS

Clarissa Hirawat  
Chair, Public Affairs Junior Manager, EURORDIS

Claudia Hirawat  
Chair of International Circle of Ambassadors, EURORDIS

BJ Holtgrewe  
Photographer

Carmelo Inguanez  
Permanent Representative, Permanent Mission of Malta to the UN

Gunilla Jaeger  
Chief of operations, Agrenska

Dirk Jakobi  
Second Secretary, Permanent Mission of Germany to the UN

Alireza Javaheri  
Counsellor on UNFPA, UNICEF, UN Women, SRHR, HIV/AIDS, Health, Permanent Mission of Sweden to the UN

Richard Jordan  
Director of UN Operations, The Royal Academy of Science International Trust

Margaretha Jones-Eggenberger  
UN Representative, International Humanist and Ethical Union

Sven Jürgenson  
Permanent Representative, Permanent Mission of Estonia to the United Nations

Elizabeth Katz  
Publisher, Neurology Reviews

Lisa Kearns  
Research associate at the Division of Medical Ethics, NYU School of Medicine
<table>
<thead>
<tr>
<th>Name</th>
<th>Position/Role</th>
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<tbody>
<tr>
<td>Nancy Kelly</td>
<td>Executive Director, Health Volunteers Overseas</td>
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<td>Katherine Klein</td>
<td>UN Volunteer, ICC</td>
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<td>Bruce Knotts</td>
<td>Director, Unitarian Universalist UN Office</td>
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<td>Mark Krueger</td>
<td>President, MK&amp;A</td>
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<td>Yann Le Cam</td>
<td>Chief Executive Officer, EURORDIS</td>
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<tr>
<td>Yee Seng Lee</td>
<td>President, Malaysia Lysosomal Diseases Association</td>
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<td>Bette Levy</td>
<td>Main UN Representative, Soroptimist International</td>
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<td>Veronica Lopez</td>
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<td>Flaminia Macchia</td>
<td>Director of Government Affairs and Public Policy, Vertex</td>
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<td>Paul Melmeyer</td>
<td>Associate Director of Public policy, National Organization for Rare Disorders (NORD)</td>
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<td>Nata Menabde</td>
<td>Executive Director of WHO Office at the United Nations, New York</td>
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<td>Abbey Meyers</td>
<td>President Emeritus, National Organization for Rare Disorders (NORD)</td>
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<td>Irina Myasnikova</td>
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<td>Cyril Ritchie</td>
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<td>Min Chieh Tseng</td>
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<td>Jeffrey T. Tseng</td>
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<td>Hassan Vahidinezhad</td>
<td>Visiting Scholar scientist and research assistant , Department of Dermatology and Cutaneous Biology, Thomas Jefferson University, Representative of Rare disease foundation of Iran (RADOIR)</td>
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<td>Philip Jonathan Vickers</td>
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<td>Inger Wästberg</td>
<td>Former Director General Swedish government</td>
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<td>Alain Weill</td>
<td>President of the Board, World Federation of Hemophilia</td>
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<td>Durhane Wong-Rieger</td>
<td>President and CEO, Canadian Organization for Rare Disorders (CORD)</td>
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<td>Rachel Yang</td>
<td>Director of International Affairs, Chinese Organization for Rare Disorders (CORD)</td>
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<td>Visiting scholar Scientific and research assistant at the Department of Dermatology and Cutaneous Biology, Thomas Jefferson University, Philadelphia, PA, USA</td>
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