RDI JOINT DECLARATION

“Rare Diseases: an International Public Health Priority” - Recommendations:

1. Enhanced Visibility
2. Patient Empowerment
3. Creation and Dissemination of Information
4. International cooperation in services to patients
5. Improve prevention, screening and timely diagnosis
6. The right to Universal Access to Healthcare
7. National and international networking of specialised expertise
8. Promotion of mobility of experts and patients to access adequate care
9. International coordination of Research
The United Nations System & the Sustainable Development Goals

Clara Hervás
RDI Membership meeting 4 June 2017, Barcelona
1945: The United Nations is created and its Charter is ratified

Aim to combine efforts to reaffirm:

- Fundamental human rights
- Dignity & worth of the human person
- Equal rights of men and women
- Equal rights of large and small nations
A universal & balanced agenda

- **January 1946:** 1st resolution adopted (peaceful use of atomic energy and elimination of weapons of mass destruction)

- **1948:** Universal Declaration of Human Rights is adopted

**But...**

- **1960s-80s:** Context of Cold War

  - Development approach: South-North division
March 1995: World Summit for Social Development in Copenhagen

Determination to capture the unique possibilities offered by the end of the cold war to promote social development and social justice.

Commitments:

- Economic, political, social, cultural and legal environment enabling social development;
- Social integration based on the enhancement and protection of all human rights;
- Universal and equitable access to education and primary health care;
- Development of Africa and developing countries
September 2000: UN Millennium Summit – Millennium Development Goals

- Set for 2000-2015
- Big focus on developing countries
- Working in silos

1. Eradicate extreme poverty and hunger
2. Achieve universal primary education
3. Promote gender equality and empower women
4. Reduce child mortality
5. Improve maternal health
6. Combat HIV/AIDS, malaria and other diseases
7. Ensure environmental sustainability
8. A global partnership for development
The 2030 Agenda: The Sustainable Development Goals (SDGs)

- Universal & inclusive: « Leave no one behind »
- Return to social development
- Inter-linkages
THE UNITED NATIONS SYSTEM

**New York**

- Secretary General DESA
- Security Council
- Economic and Social Council (ECOSOC)
- General Assembly
  - 193 members & Committees
- International Criminal Court
- International Court of Justice

**Geneva**

- UN Programmes & Funds
  - UNDP
  - UNHCR
  - UNICEF
  - UNEP
- Specialised Agencies
  - FAO
  - UNESCO
  - WHO
  - WTO
- CoNGO
Focus on Human Rights:

- Office of the United Nations High Commissioner for Human Rights
- United Nations Human Rights Council

Focus on the right to health: World Health Organisation (Specialised Agency)

- Communicable diseases
- Increasingly non-communicable diseases
- Access to medicines debate focused on IP and generics
Development agenda:
- ECOSOC
- DESA
  - United Nations Development Program (UNDP)

Rebirth of universal mission with SDGs

New definition of health: more than the mere absence of disease
- Health & well-being
- « Leave no one behind »
- Universal Coverage
The NGO Committee for Rare Diseases

- New York

Yann Le Cam & Clara Hervás
NGO COMMITTEE FOR RARE DISEASES

- Committee under the umbrella of Conference of NGOs in Consultative Relationship with the United Nations (CoNGO)

- **Goal:** 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).

- **Who is involved?**
  - Initiative by Ågrenska Foundation & EURORDIS - Rare Diseases Europe in cooperation with RDI
  - Supported by 34 NGOs from CoNGO
  - Forum for interested parties (NGOs, ECOSOC members, UN bodies, individual experts)
FORMAL INAUGURATION

- Friday 11 November 2016
- UN Headquarters in New York
A MILESTONE IN THE JOURNEY TO PUT RARE DISEASES IN THE GLOBAL AGENDA

Founding Act

« Rare Diseases and the UN Sustainable Development Goals »
New York City, Friday 11 November 2016

We, the undersigned participants to the inaugural « Global Gathering for Rare Diseases », proclaim and endorse the following statements:

- Each of the 6,000 reported rare diseases affects a very small population locally. **All together, however, they represent an international public health issue.**
- The 350 million persons living with a rare disease worldwide are facing common challenges across diseases and across borders that affect all parts of their lives at once.
- **No one country, no one continent alone can solve the problems posed by rare diseases.**
- Experience shows that actions are possible and effective. Common national policies and international collaboration can address these challenges.
- Scientific, medical, technological, social opportunities will be high in the next 20 years. **Patients, NGOs and other stakeholders are committed and aligned for partnership.**
- Rare diseases fit within the objectives from several UN SDGs and can significantly contribute to their achievement.

The NGO Committee for Rare Diseases will catalyse all efforts towards the delivery of the SDGs in support of rare diseases, and towards the recognition and integration of rare diseases in all relevant future global policy and initiatives of the United Nations and its agencies.
STRATEGY

From civil society:

- NGOs in dialogue with UN: CoNGO
- Agrenska, EURORDIS & a wider global voice: RDI
- Legitimacy & people-centred

Position ourselves in the New York « bubble »:

- General angle: Social Development = health + social aspects
- Specific angle:
  - Leveraging SDGs - great number of synergies with RDs
  - ECOSOC & DESA (DSPD division: youth, older persons, disabilities, families, indigenous people)
  - General Assembly
## SDGs & RARE DISEASES: SYNERGIES

<table>
<thead>
<tr>
<th>SDGs</th>
<th>Rare Diseases Challenges</th>
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<tr>
<td>1 NO POVERTY</td>
<td>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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<tr>
<td>3 GOOD HEALTH AND WELL-BEING</td>
<td>Universal health coverage = more and better medicines, appropriate diagnosis and lifelong care and social support</td>
</tr>
<tr>
<td>4 QUALITY EDUCATION</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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SDGs & RARE DISEASES: SYNERGIES

**SDGs**

1. **Gender Equality (5)**
   - Gender equality = Recognising and valuing unpaid care and domestic work that many mothers of children (including when they are grown adults) with rare diseases take on.

2. **Decent Work and Economic Growth (8)**
   - Persons with rare diseases and disabilities are often marginalised from job markets due to lack of accessible facilities, flexible working hours and adapted roles.

3. **Industry, Innovation and Infrastructure (9)**
   - Need to invest in research & development of therapies, health technologies and diagnostic tools.
   - Accessibility to infrastructure is key to being included in society.
## SDGs & RARE DISEASES: SYNERGIES

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<td>10</td>
<td>Marginalised and invisible population suffering from discrimination in the health, labour and governance fields</td>
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<td>17</td>
<td>The rare disease community is increasingly interconnected, with a myriad of networks of patient advocates, regulators, research &amp; industry</td>
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<td>The NGO Committee for Rare Diseases embodies this goal as multi-stakeholder partnerships are enshrined in its by-laws</td>
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“Rare diseases have a health & social impact - so they need to be considered and they have a space in the United Nations agenda”

Daniela Bas, DSPD division, DESA
"If we are serious about leaving nobody behind we cannot leave behind those living with a rare disease just because they are few“

Nata Menabde, Executive Director, World Health Organization Office at the United Nations
FUTURE ACTIONS FOR THE COMMITTEE

- Progressive Membership-building & Activities
- Learning curve (policies, process, people...)
- ECOSOC: raise awareness on RDs (attend key events; contribute to policies on health, social aspects, disability...; start to exist in the UN system)
- Baby steps towards UN resolution on rare diseases
FIRST RARE DISEASE POLICY EVENT IN GENEVA

- 

Paloma Tejada
Senior Manager, Rare Diseases International
THE RIGHT TO HEALTH:
THE RARE DISEASE PERSPECTIVE

Friday, February 10, 2017
#rdiGeneve

In partnership and with the support of:

BLACKSWAN FOUNDATION

EURORDIS RARE DISEASES EUROPE
WITH THE PARTICIPATION OF
FIRST INTERNATIONAL RARE DISEASE POLICY EVENT IN GENEVA

Objectives

- Put rare diseases in the global health agenda
- Analyse barriers to research, innovation and access in order to come up with solutions

Means:

- Give visibility to RDs amongst international institutions (WHO, UNDP, OECD)
- Bring together experts from various stakeholder groups to share their ideas and trigger future collaborations (patients, researchers, industry, academia, policy-makers, health economists)

New angle: RD from Human Rights perspective

- 20 speakers & panellists
- 170 registered participants – 140 attendants
- Livestream throughout the day (up to 369 views)
Daininus Puras, United Nations Special Rapporteur on the Right to Health

« We need to do our best to secure that children affected by rare diseases have the right - like all children - to health, good quality of live, holistic development, good quality of treatment, care and support »

“What we need today is raising of awareness and mobilisation of will of main stakeholders globally so that existing gaps in research and early identification and treatment of rare diseases is effectively closed and discrimination of PLWRD is put to an end.”
«I am moved and impressed by the coalition of all different kind of patients who suffer from very different diseases but have the common need to break the silence and isolation and become worldwide lobby..

Some countries are pioneers, others are coming now to this large movement...

The idea that there is a worldwide organisation is very important

A worldwide organisation that can bring the discussion on the level where it needs to be brought : On the political level in each country and at international level in the UN system”
“Governments are ultimately responsible for ensuring access

We need to start promoting cheaper generic development of these drugs

WHO works on quality assurance of drugs produced in developing countries for Hep C and HIV AIDS

We can work together to make it happen for rare disease as well”
MAIN POLICY MESSAGES – RESEARCH & ACCESS

- Nb of ODs is increasing which is good news
- More active substances approved by regulators
- Good business opportunity for developers
- But budget impact becoming higher as is opportunity cost in other areas of health spending
- Gaps in the incentive system in the whole chain of R&D of from basic research to treatments
- Partnership is key because there are many actors in this chain and they depend on each other
- State and industry have to work together
TOWARDS A NEW PARADIGM FOR RARE DISEASES

- Need a paradigm shift to go from basic research to affordable treatments
- Basic research has to remain mainly in the hands of the public sector
- RD most visible case of need not to rely only on IP mechanisms but to build partnerships b/w public sector and scientific community in universities
- Response has to be global- no solution will come at national level exclusively
Statement of Support of Dr. Tedros Adhanom Ghebreyesus
new Director-General of the World Health Organisation
Towards a UN GA Resolution

What, why, how?

Clara Hervás & Yann Le Cam
WHAT IS A UN GENERAL ASSEMBLY RESOLUTION?

- The term « UN resolution » can mean many things: GA, Security council, WHA, ECOSOC
- GA Resolution = member states views
- Binding on the UN Funds & Programmes (UNDP, UNICEF)
- Not binding on Specialised Agencies (WHO) - but influence as de facto coordinator of UN system
Resolution adopted by the General Assembly

[on the report of the Second Committee (A/74/444)]

74/333 The promotion of chocolate for the physical and mental well-being of people

The General Assembly,

Reaffirming its previous resolutions relating to the issue of chocolate, including resolution 45/77 of 12 December 1990 and 63/509 of 14 September 2009;

Recognizing the role of the General Assembly in addressing the issue of chocolate, in accordance with the Charter of the United Nations;

Recognizing also the need to further enhance the role, authority, effectiveness and efficiency of the General Assembly;

1. Takes note of the report of the Secretary-General on “Chocolate for All”;

2. Expresses its support for the ongoing promotion of chocolate for the physical and mental well-being of people;

3. Calls upon the Secretary-General to mainstream the use of chocolate as a tool to increase gross national happiness throughout the United Nations system and its operational activities;

4. Encourages Member States to promote the consumption of chocolate;

5. Decides to declare 2020 the International Year of Chocolate.

6. Requests the Secretary-General to submit a report on the implementation of the present resolution, including recommendations for future action, at the eighty-fourth session of the General Assembly.

62nd plenary meeting
21 October 2019
HEALTH GA RESOLUTIONS: A MAPPING

3 identified types:

a) Simple and targeted towards recognition of awareness-raising day

b) Content-rich and requesting more substantial action

c) The Foreign Policy and Health Initiative Group resolution
a) SIMPLE/AWARENESS-RAISING RESOLUTIONS

Examples:

- Recognition of sickle-cell anaemia as a public health problem (2008)
Examples:

- 58/173. *The right of everyone to the enjoyment of the highest attainable standard of physical and mental health* (2003)
c) FOREIGN POLICY AND HEALTH INITIATIVE RESOLUTION (HEALTH DIPLOMACY)

- Initiative started in 2006 by Norway and France - Oslo Ministerial Declaration

- Group of 7 countries with different levels of development: Brazil, France, Indonesia, Norway, Senegal, South Africa and Thailand.

- Each country coordinates the group for a year on a rotating basis (Thailand in 2017)

- Annual resolution presented to the GA in autumn

- First negotiated by the 7 Permanent Missions to UN in Geneva - following WHO activities
Examples:

- A/RES/68/98 Partnerships for global health (2013)
- A/RES/70/183 Strengthening the management of international health crises (2015)
- A/RES/71/159 Health employment and economic growth (2016)
UN GA Resolutions require support of at least one UN Member State as sponsor

Process:

1) Sponsor drafts resolution and sends to Sec-Gen
2) Tabled as agenda item to be dealt by Third Committee (Social, Humanitarian & Culture)
3) The Committee recommends resolution to the GA Plenary
4) The GA Plenary adopts via consensus or vote (depending on how Committee agreed).
Strategy wrap-up

&

How RDI and its members can contribute
NGO COMMITTEE FOR RARE DISEASES

- Progressive build-up of membership and activities
- RDI - member of NGO Committee for RDs
- RDI can co-produce activities with NGO Committee e.g. State of the Art; Reports...
- Some members of RDI can also be direct members of the NGO Committee for RDs
ACTION WITHIN ECOSOC

Objective:
- Raise awareness
- Gain recognition
- Contribute to relevant policies

Where?
- High-Level Political Forum
- Conference of States on Convention on the Rights of People with Disabilities
- Right to health & access debates at the WHO

How? Use position papers/contributions from RDI and its members
BABY STEPS TOWARDS GA RESOLUTION

Integrate mention to rare diseases into the Foreign Policy and Health Initiative resolution

Draft our ideal UN Resolution on Rare Diseases involving the members of RDI

Advocate to country’s

- Ministry of Foreign Affairs
- Ministry of Health
- Permanent Representations in New York and Geneva
THANK YOU