Rare Diseases International

Activity & Financial Report 2019

A strong common voice for people living with a rare disease around the world

RARE
DISEASES
INTERNATIONAL

2019 Highlights

Legal Incorporation

January

RDI 5th Annual Meeting

February

RDI met with Dr Tedros, Director-General of the WHO, to discuss future collaboration

March

Campaign with National Alliances to include RD in UN Political Declaration

May

RDI signs an Memorandum of Undrerstanding with WHO

September

February

RDI participated in Rare Disease Day policy event at the United Nations

March

Rare Disease Side Events at WHO 72 World Health Assembly

July

December

RDI –IFPMA Round Table on Access in LMICs

RARE DISEASES INTERNATIONAL

Governance and Membership

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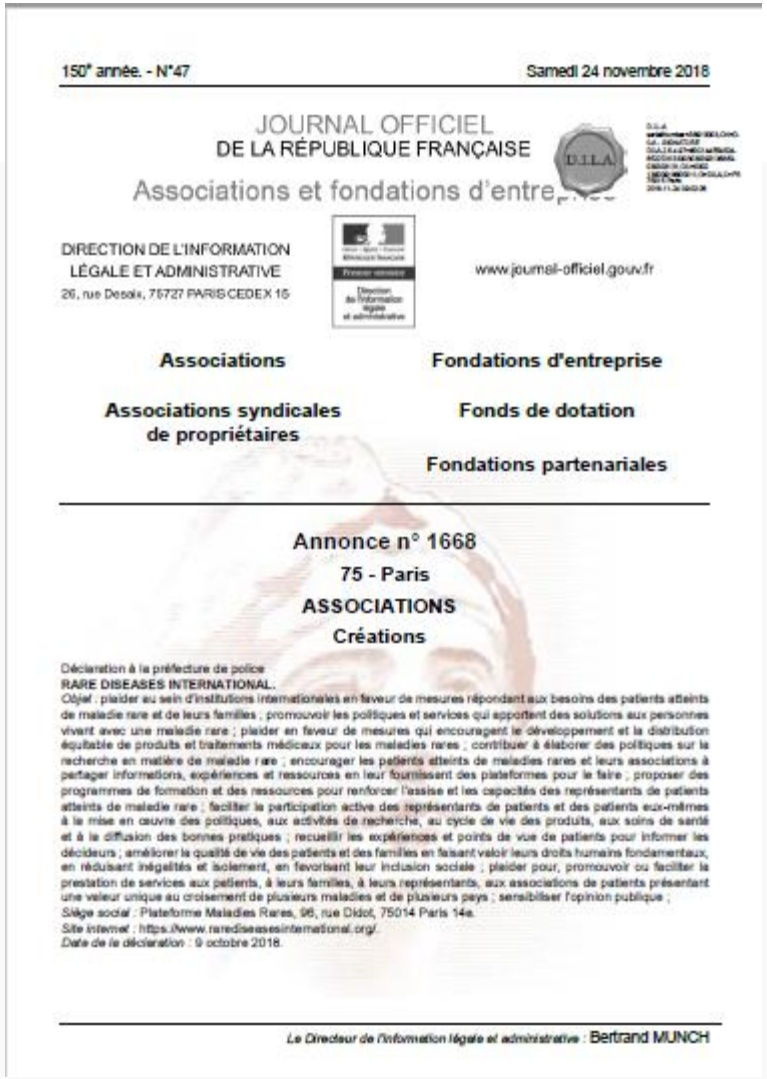
Legal incorporation

RDI was incorporated un under French law as an Association Loi 1901 on December 7, 2018

RDI has been operating as legally-registered organisation since January 2019

The Statutes (constitution) of the organisation can be found on the website: https://www.rarediseasesinternational.org/governance/

New By-Laws (internal rules) adopted in 2020



150e année. - N°47 Samedi 24 novembre 2018

JOURNAL OFFICIEL
DE LA RÉPUBLIQUE FRANÇAISE

Associations et fondations d'entreprise

DIRECTION DE L'INFORMATION LÉGALE ET ADMINISTRATIVE
26, rue Desaix, 75727 PARIS CEDEX 15

www.journal-officiel.gouv.fr

Associations | **Fondations d'entreprise**

Associations syndicales de propriétaires | **Fonds de dotation**

Fondations partenariales

Annonce n° 1668

75 - Paris

ASSOCIATIONS

Créations

Déclaration à la préfecture de police
RARE DISEASES INTERNATIONAL.
Objet : plaider au sein d'institutions internationales en faveur de mesures répondant aux besoins des patients atteints de maladie rare et de leurs familles ; promouvoir les politiques et services qui apportent des solutions aux personnes vivant avec une maladie rare ; plaider en faveur de mesures qui encouragent le développement et la distribution équitable de produits et traitements médicaux pour les maladies rares ; contribuer à élaborer des politiques sur la recherche en matière de maladie rare ; encourager les patients atteints de maladies rares et leurs associations à partager informations, expériences et ressources en leur fournissant des plateformes pour le faire ; proposer des programmes de formation et des ressources pour renforcer l'assise et les capacités des représentants de patients atteints de maladie rare ; faciliter la participation active des représentants de patients et des patients eux-mêmes à la mise en œuvre des politiques, aux activités de recherche, au cycle de vie des produits, aux soins de santé et à la diffusion des bonnes pratiques ; recueillir les expériences et points de vue de patients pour informer les décideurs ; améliorer la qualité de vie des patients et des familles en faisant valoir leurs droits humains fondamentaux, en réduisant inégalités et isolement, en favorisant leur inclusion sociale ; plaider pour, promouvoir ou faciliter la prestation de services aux patients, à leurs familles, à leurs représentants, aux associations de patients présentant une valeur unique au croisement de plusieurs maladies et de plusieurs pays ; sensibiliser l'opinion publique ;
Siège social : Plateforme Maladies Rares, 96, rue Didot, 75014 Paris 14e.
Site internet : https://www.rarediseasesinternational.org/.
Date de la déclaration : 9 octobre 2018.

Le Directeur de l'information légale et administrative : Bertrand MUNCH

Governance: RDI council

Durhane Wong-Rieger
CORD
Canada

Lisa Sarfaty
NORD

Yann Le Cam
EURORDIS

Ritu Jain
DEBRA International

Kin Ping Tsang
Retina International

Rachel Yang
CORD
China

Jesús Navarro
ALIBER

Governance: RDI Advocacy Committee

Yan Lee Cam
EURORDIS
Chair

Maureen Smith
CORD-Canada

Ritu Jain
DEBRA
International

Kelly du Plessis
RDSA-South Africa

Ramaiah Muthyala
IORD-India

Lara Bloom
EDS-UK

Leire Solis
IPOPI

Luciana Escati
FADEPOF

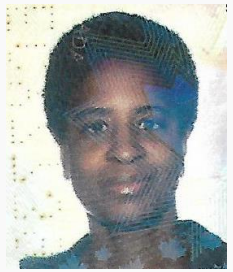
Eleni Antoniou
Thalassaemia
International

Sanja Peric
RD-Croatia

Migdalia Denis
PHLS

Lieven Bauwens
IFSBH

Alba Ancochea
FEDER-Spain



Heather Richards
WFH

Simone Boselli
EURORDIS

Kawaldip Sehmi
IAPO

Roberta Anido de Pena
FADEPOF

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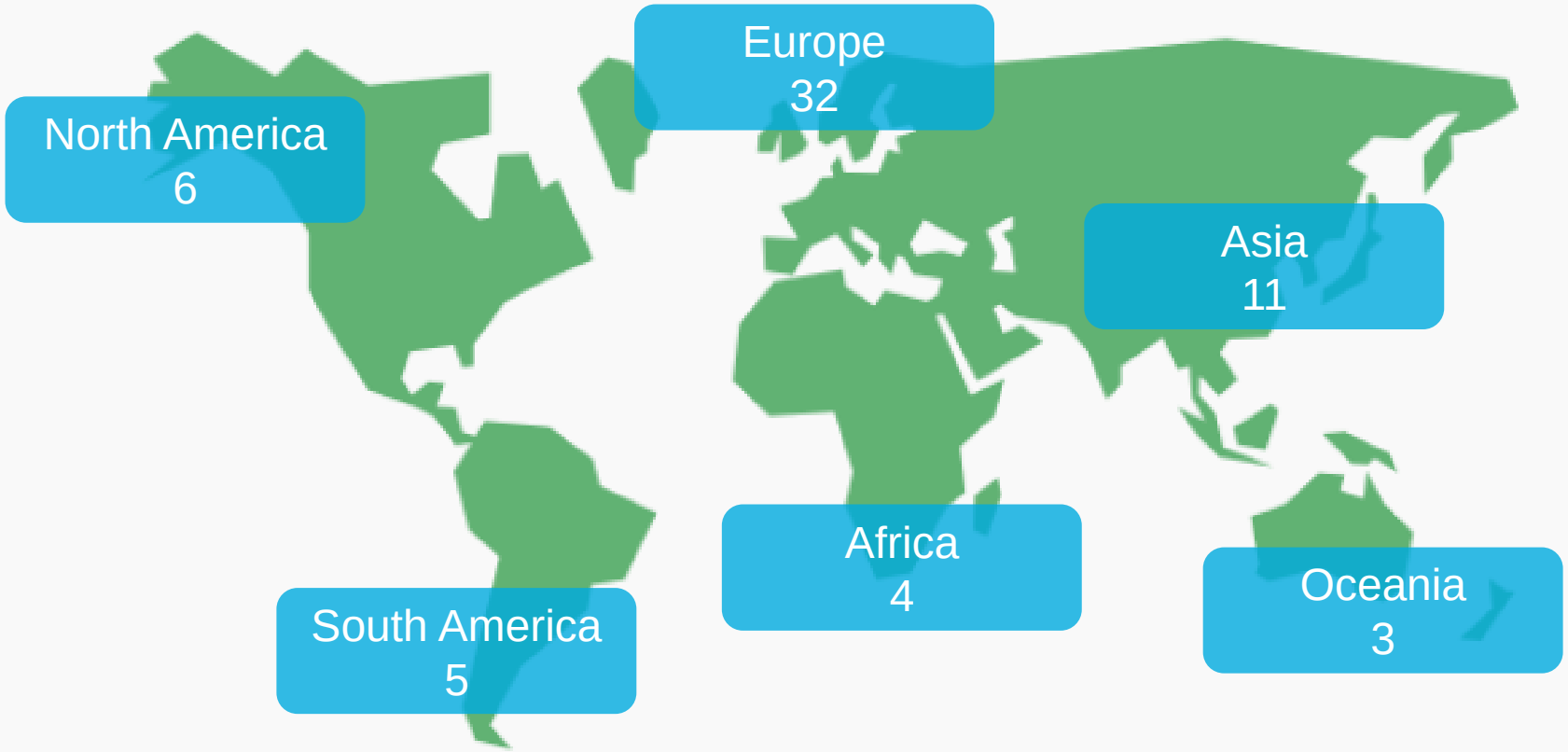
Membership in 2019

62 member organisations, present in over 100 countries

- 35 national alliances
- 17 international federations
- 3 regional networks
- 7 other rare disease organisations



RDI 6th Annual Meeting

- February 20th at the Microsoft Global Headquarters in New York, USA
- First time oustside Europe
- Launch of the Recommendations Report of the Global Commission to End the Diagnosis Odyssey of Children with a Rare Disease
- NGO Committee for Rare Diseases High Level Event Rare Disease Day at the UN Event
- 32 member organisations from 26 countries at General Assembly and Membership Meeting
- 119 delegates at RDI Global Meeting

Communication & Engagement

- Outreach and Engagement Manager

  - Hlawulani Mkhabela

- Monthly RDI e-newsletter

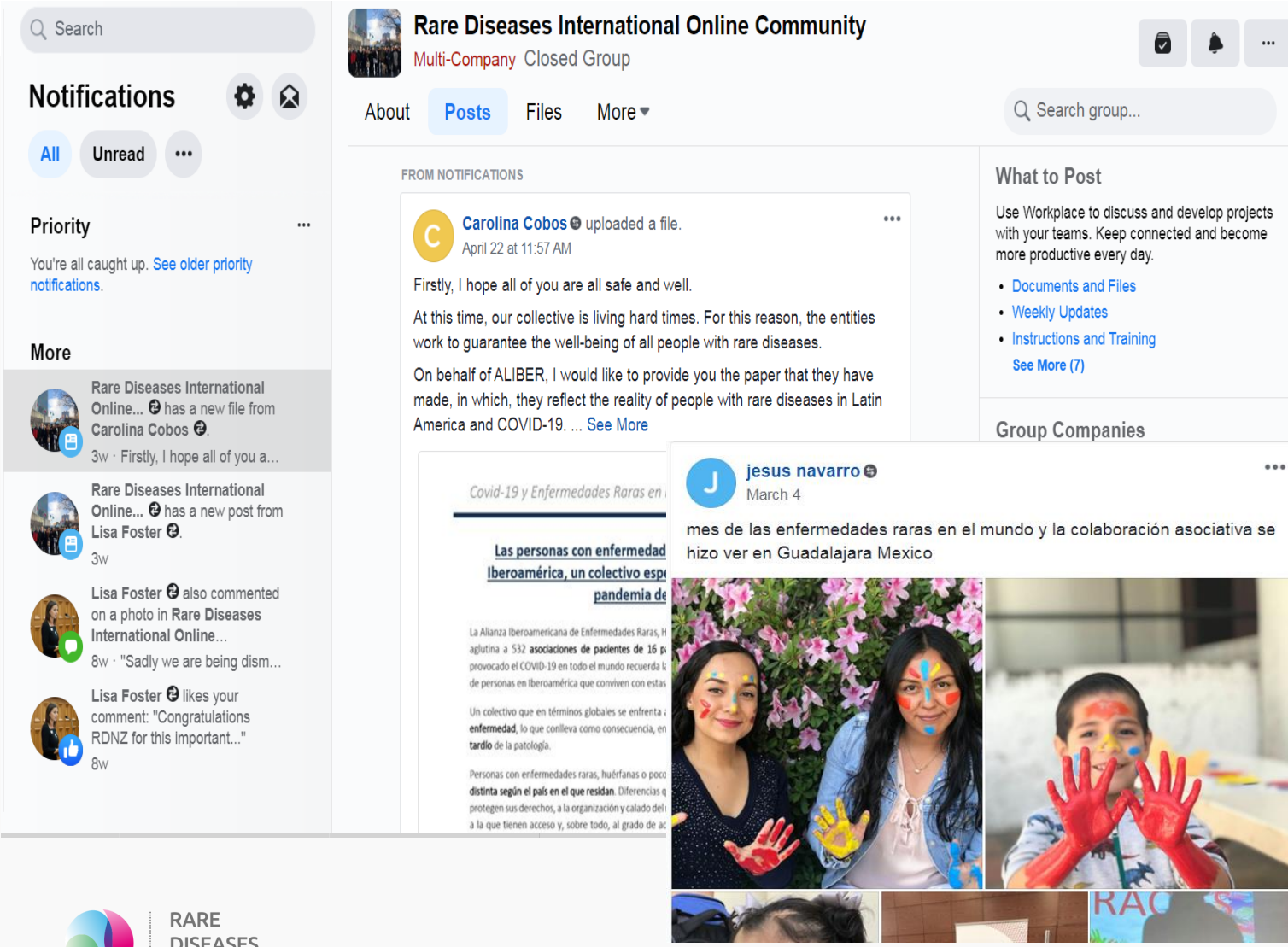
  - sharing news, events, calls for input and action

- Launch Facebook Workplace group

  - online community for RDI members to connect with each other, share news and best practice and ask for guidance

- Social media – Twitter +2000 followers

- RDI National Alliance involvement in Rare Disease Day



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Funding and Programmes

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RDI Alliance of Companies

A platform for companies across different sectors to support the rare disease cause internationally and to increase mutual understanding of issues that are important for rare disease patients and different industries.

In 2019:

- 9 companies joined the Alliance
- Met for first on-line meeting on August 29 to learn more about

RDI Advocacy strategy and inclusion of rare disease in UN Political Declaration on UHC

RDI Conference Programme

1. *Rare Disease Day at the UN Event, Global Commission Report Launch, New York, Feb 20-21* ***level 3***

2. *World Orphan Drug Congress, Washington DC, April* ***level 2***

3. *Canadian Organization for Rare Disorders/ ReACT Conference, Toronto, Canada, May 9-13* ***level 3***

4. '*Rare Diseases: A global challenge, a holistic challenge' Conference at the National Rare Disease Centre (CREER), Burgos, Spain, September 19-20* ***level 2***

5. *APARDO Summit 'Regional Collaboration for Global Change', Taipei, Taiwan, October 19-21* ***level 3***

6. *XIV International Conference on Rare Diseases and Orphan Drugs" (ICORD), Tel Aviv, Israel, November 11-13* ***level 2***

7. *World Orphan Drug Congress, Barcelona, Spain, November 12-14* ***level 2***

8. *VI Encuentro Iberoamericano de Enfermedades Raras (ALIBER 6th Conference) Murcia, Spain, November 13-15* ***level 1***

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RDI Fellowship Programme

Rare Disease Day at the UN Event / Global Commission Report Launch, New York, Feb 20-21 ***level 3***

► RDI financial support for patient representatives to participate (17 fellowships)

Canadian Organization for Rare Disorders 'A Rare International Dialogue" Conference, Toronto, Canada, May 9-13 ***level 3***

► RDI financial support for patient representatives to participate (9 fellowships)

APARDO Summit 'Regional Collaboration for Global Change', Taipei, Taiwan, October 19-21 ***level 3***

► RDI financial support for patient representatives to participate (16 fellowships)

Advocacy

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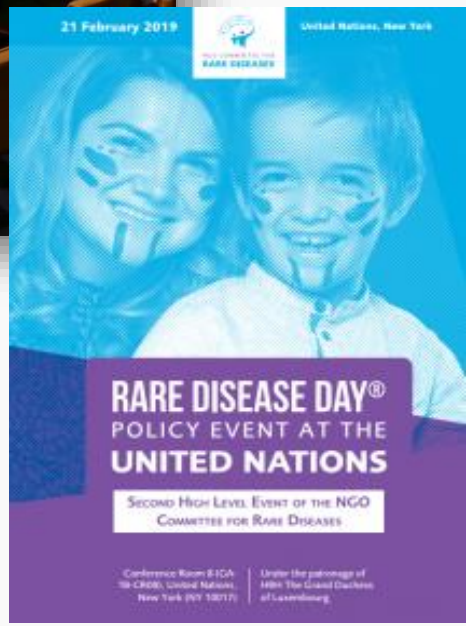
Rare Disease Day at UN Event

Rare Disease Day Policy Event at the United Nations Headquarters

Co-organisers NGO Committee for Rare Diseases, EURORDIS – Rare Diseases Europe and RDI

21 February 2019, United Nations Headquarters, New York

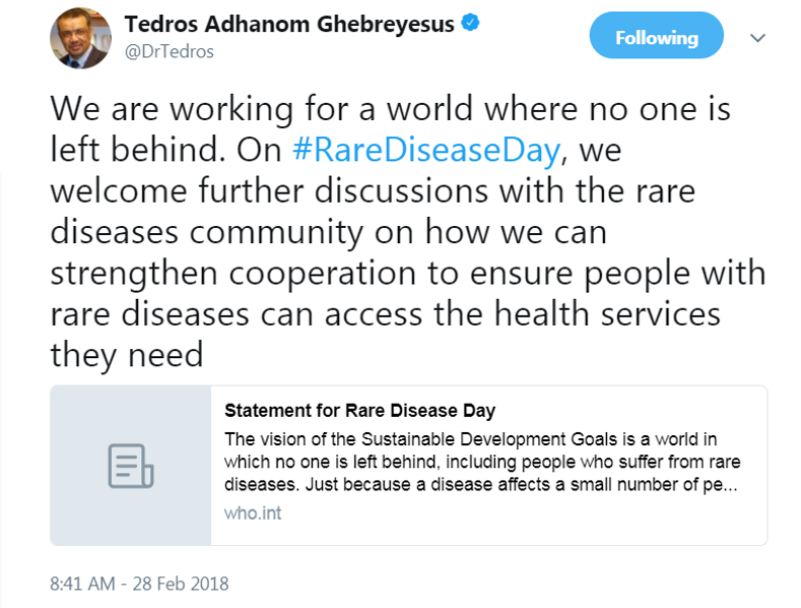
- 15 countries co-hosted the event at UN Headquarters building in New York



Making the voices of PLWRDs heard at heart of UN

- Over 100 participants from the international NGO community, UN agencies, national governments, academic institutions, the private sector and the rare disease patient community came together at the United Nations Headquarters in New York.
- 40 patient advocates from RDI member organisations were invited to participate and represent the rare disease patient community.
- 17 RDI fellowships for patient advocates to attend

Collaboration with WHO



- RDI and WHO Secretariat identified areas of collaboration to shape a partnership, which will be formalised in a Memorandum of Understanding.
- Collaboration based on ambitious goals that contribute to WHO's 13th General Programme of Work
- Prepare the ground for RDI to be NSA in official relations with WHO
- Will enable RDI to carry our programmes and shape the agenda from within (as NSA official relations)

On 18 March 2019, Yann Le Cam and Durhane Wong-Rieger met with Dr Tedros, Director-General of the WHO, in Geneva

Position of RD patient community on UHC

- Paper released in April 2019 adopted by RDI Council in consultation with RDI Advocacy Committee
- Input and case studies from RDI members
- Important advocacy tool in inclusion of RDs in UHC campaign
- Paper available on RDI website: www.rarediseasesinternational.org


RARE DISEASES INTERNATIONAL

Position Paper « Rare Diseases: Leaving No One Behind in Universal Health Coverage » April 2019

Rare Diseases:

Leaving no one behind in

Universal Health Coverage

"We must work together to ensure an equitable and affordable access to quality health services and medicines for everyone, especially people who are most in need, which also includes people living with rare diseases, while ensuring that they do not face financial hardship or fall back into poverty because of their catastrophic medical expenses. This is in line with our commitment in the 2030 Agenda to leave no one behind. Millions of people around the world are suffering from rare diseases, which require some of the most advanced and expensive forms of treatment and interventions. As a result, these people and their families carry very high burden in many aspects of life – physically, financially and socially."

H.E. Vitavas Srivihok, Ambassador and Permanent Representative, Permanent Mission of Thailand to the UN, Co-Facilitator for the Negotiation of the Political Declaration of the High-Level Meeting on UHC 21 February 2019

"WHO's top priority is to support countries on the path towards universal health coverage, with the aim of ensuring that all people can access the health services they need. (…) This includes access to diagnosis and treatment for people who suffer from rare diseases."

Dr Tedros Adhanom Ghebreyesus, WHO 28 February 2018

www.rarediseasesinternational.org 1 / 34

Rare Disease Side events at WHO 72nd World Health Assembly

RARE DISEASES INTERNATIONAL

Side Event
World Health Organization
72nd World Health Assembly

UNIVERSAL HEALTH COVERAGE: INCLUDING RARE DISEASES TO LEAVE NO ONE BEHIND

THURSDAY 23 MAY 2019 - 18.00 - 20.00
International Red Cross and Red Crescent Museum
Salle Henry Dunant
Avenue de la Paix, 1202 Geneva
(opposite Palais des Nations)

This informal side event will promote awareness and knowledge on the topic Rare Diseases and serve to unite the international community, patients and all relevant stakeholders to address the unmet needs of this vulnerable population within Universal Health Coverage.

PROGRAMME

17.30 WELCOME DRINKS

18.00-18.30

OPENING REMARKS – **Dr Durhane Wong-Rieger**, Chair, Rare Diseases International and President & CEO, Canadian Organization for Rare Disorders

KEYNOTE ADDRESS – **Mr Todd Howland**, Chief of the Development and Economic and Social Issues Branch, Office of the United Nations High Commissioner for Human Rights

GLOBAL FIGURES, DEFINITION AND VISIBILITY – Video presentation by **Dr Ana Rath**, Director, Orphanet INSERM

HOPES AND CHALLENGES OF PEOPLE LIVING WITH A RARE DISEASE – **Mr Yann Le Cam**, Chief Executive Officer, EURORDIS-Rare Diseases Europe and Treasurer of the Council of Rare Diseases International

18.30 - 19.30

STRATEGIES TO ADDRESS RARE DISEASES WITHIN UNIVERSAL HEALTH COVERAGE
Panel Discussion moderated by Durhane Wong-Rieger

INCLUDING RARE DISEASES IN THE NATIONAL HEALTH SYSTEM - THE CASE OF THE PHILIPPINES - **Dr Carmencita Padilla**, Professor of Paediatrics at the College of Medicine and Chancellor of University of the Philippines Manila

PREVENTION AND EARLY INTERVENTIONS - THE CASE OF SPINA BIFIDA AND HYDROCEPHALUS - **Mr Lieven Bauwens**, Secretary General, International Federation for Spina Bifida and Hydrocephalus

IMPROVING DIAGNOSIS, REDUCING MISDIAGNOSIS - THE CASE OF THALASSAEMIA
Dr Androulla Eleftheriou, Executive Director, Thalassaemia International Federation

ACCESS TO TREATMENTS PROGRAMMES - THE CASE OF HAEMOPHILIA
Mr Alain Weill, President, World Federation of Hemophilia

Q&A AND DISCUSSION

19.30- 19.45

CLOSING REMARKS: THE WAY FORWARD - **Dr Rüdiger Krech**, Director, Universal Health Coverage and Health Systems, Office of the Assistant Director-General, World Health Organization

RARE DISEASES INTERNATIONAL

RDI WHA 72 Side Event

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how transformational digital technologies can contribute to leave no one behind in universal health coverage: the case of rare diseases

Side event to the 72nd World Health Assembly
Thursday, May 23 2019
12:30-14:00
Geneva, Palais des Nations, Room XXIII

Rare diseases are at the forefront of digital health and exemplify high added value of regional and global approaches. New digital tools are already being used to address the challenges of the 300 million people living with a rare disease to connect highly isolated patients, enable access and speed up diagnosis, refer to specialized medical expertise, to gather and share expertise on highly complex care, and accelerate clinical research. This side event will serve to show the potential of digita health to achieve Universal Health Coverage, using rare diseases as an example.

Opening remarks:

Ambassador **Walter Stevens**
Head of the EU Delegation to the UN in Geneva

Dr. **Soumya Swaminathan**
Chief Scientist, WHO

Keynote speeches:

Dr. **Cristian Grasu**
Secretary of State, Ministry of Health, Romania

Prof. Dr. **Ildikó Horváth**
Minister of State for Health
Ministry of Human Capacities, Hungary

PANELISTS

Dr. **Chieko Ikeda**, Senior Assistant Minister for Global Health, Minister's Secretariat, Ministry of Health, Labour and Welfare of Japan
Martin Seychell, Deputy Director-General DG SANTE, European Commission
Yann Le Cam, Founder and Chief Executive Officer of EURORDIS – Rare Diseases Europe

Closing Remarks: Dr. **Soumya Swaminathan** - Chief Scientist, WHO

Moderator: **Durhane Wong- Rieger -** Chair of Rare Diseases International and CEO of Canadian Organization for Rare Disorders

Sandwiches will be served prior to the event.

romania2019.eu
Romanian Presidency of the Council of the European Union

GOBIERNO DE COLOMBIA

Kingdom of the Netherlands

Government Offices of Sweden

Permanent Mission of Hungary to the UN in Geneva

Liberté • Égalité • Fraternité
RÉPUBLIQUE FRANÇAISE
REPRÉSENTATION PERMANENTE DE LA FRANCE AUPRÈS DES NATIONS UNIES À GENÈVE ET DES ORGANISATIONS INTERNATIONALES EN SUISSE

Formal Side Event: First time RD at WHA

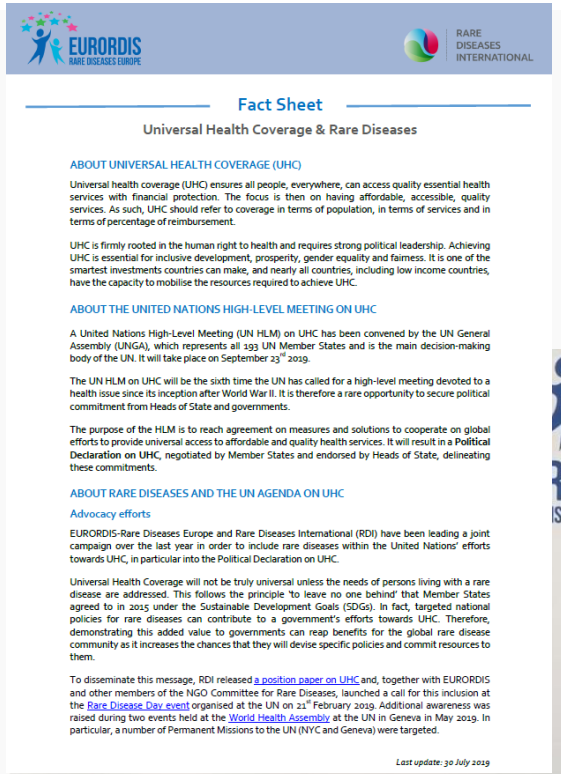
RARE DISEASES INTERNATIONAL

RDI and EURORDIS Joint Campaign

- Inclusion of Rare Diseses in the UN Political Declaration on UHC
- Toolkit for National Alliances to advocate to Ministries of Health and Foreign Affairs; and to Permanent Missions to the United Nations

- 13 National alliances participated!

Argentina, Austria, China, Colombia, Germany, Greece, India, Luxembourg, Malaysia, New Zealand, Romania, Serbia, Spain.



EURORDIS RARE DISEASES EUROPE

RARE DISEASES INTERNATIONAL

Fact Sheet

Universal Health Coverage & Rare Diseases

ABOUT UNIVERSAL HEALTH COVERAGE (UHC)

Universal health coverage (UHC) ensures all people, everywhere, can access quality essential health services with financial protection. The focus is then on having affordable, accessible, quality services. As such, UHC should refer to coverage in terms of population, in terms of services and in terms of percentage of reimbursement.

UHC is firmly rooted in the human right to health and requires strong political leadership. Achieving UHC is essential for inclusive development, prosperity, gender equality and fairness. It is one of the smartest investments countries can make, and nearly all countries, including low income countries, have the capacity to mobilise the resources required to achieve UHC.

ABOUT THE UNITED NATIONS HIGH-LEVEL MEETING ON UHC

A United Nations High-Level Meeting (UN HLM) on UHC has been convened by the UN General Assembly (UNGA), which represents all 193 UN Member States and is the main decision-making body of the UN. It will take place on September 23rd 2019.

The UN HLM on UHC will be the sixth time the UN has called for a high-level meeting devoted to a health issue since its inception after World War II. It is therefore a rare opportunity to secure political commitment from Heads of State and governments.

The purpose of the HLM is to reach agreement on measures and solutions to cooperate on global efforts to provide universal access to affordable and quality health services. It will result in a **Political Declaration on UHC**, negotiated by Member States and endorsed by Heads of State, delineating these commitments.

ABOUT RARE DISEASES AND THE UN AGENDA ON UHC

Advocacy efforts

EURORDIS-Rare Diseases Europe and Rare Diseases International (RDI) have been leading a joint campaign over the last year in order to include rare diseases within the United Nations' efforts towards UHC, in particular into the Political Declaration on UHC.

Universal Health Coverage will not be truly universal unless the needs of persons living with a rare disease are addressed. This follows the principle 'to leave no one behind' that Member States agreed to in 2015 under the Sustainable Development Goals (SDGs). In fact, targeted national policies for rare diseases can contribute to a government's efforts towards UHC. Therefore, demonstrating this added value to governments can reap benefits for the global rare disease community as it increases the chances that they will devise specific policies and commit resources to them.

To disseminate this message, RDI released a position paper on UHC and, together with EURORDIS and other members of the NGO Committee for Rare Diseases, launched a call for this inclusion at the Rare Disease Day event organised at the UN on 21st February 2019. Additional awareness was raised during two events held at the World Health Assembly at the UN in Geneva in May 2019. In particular, a number of Permanent Missions to the UN (NYC and Geneva) were targeted.

Last update: 30 July 2019

Take action: advocate on inclusion of rare diseases in UHC

Rare Diseases included in political declaration on UHC

- **UN Political Declaration on UHC adopted at High-Level Meeting on UHC during UNGA 74th Session (23 September 2019)**
- Adopted by 193 Member States an endorsed by all Heads of State
- **First time rare diseases included in a text adopted by UN General Assembly**

United Nations A/RES/74/2

General Assembly

Distr.: General
18 October 2019

Seventy-fourth session
Agenda item 126
Global health and foreign policy

Resolution adopted by the General Assembly on 10 October 2019

[*without reference to a Main Committee (A/74/L.4)*]

74/2. Political declaration of the high-level meeting on universal health coverage

MOVING TOGETHER
TO BUILD A HEALTHIER WORLD

UN High-Level Meeting on Universal Health Coverage, 23 September 2019, New York

Page 4: *We therefore commit to scale up our efforts and further implement the following actions:*

24. Accelerate efforts towards the achievement of universal health coverage by 2030 to ensure healthy lives and promote well-being for all throughout the life course, and in this regard reemphasize our resolve to:

a. progressively cover one billion additional people by 2023 with quality essential health services and quality, safe, effective, affordable and essential medicines, vaccines, diagnostics and health technologies, with a view to cover all people by 2030;

b. stop the rise and reverse the trend of catastrophic out-of-pocket health expenditure by providing measures to assure financial risk protection and eliminate impoverishment due to health-related expenses by 2030, **with special emphasis on** the poor as well as **those who are vulnerable** or in vulnerable situations;

25. Implement most effective, high impact, quality-assured, people-centred, gender- and disability-responsive, and evidence-based interventions to meet the health needs of all throughout the life course, **and in particular those who are vulnerable or in vulnerable situations,** ensuring universal access to nationally determined sets of integrated quality health services at all levels of care for the prevention, diagnosis, treatment and care in a timely manner;

34. Also strengthen efforts to address eye health conditions and oral health, as well as **rare diseases** and neglected tropical diseases, as part of universal health coverage;

RARE DISEASES INTERNATIONAL

RDI signs MOU with WHO

MEMORANDUM OF UNDERSTANDING

BETWEEN

THE WORLD HEALTH ORGANIZATION

AND

RARE DISEASES INTERNATIONAL

Introduction

WHEREAS WHO, having its headquarters in Geneva, Switzerland, is the directing and coordinating authority for health within the United Nations system. It is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries, and monitoring and assessing health trends;

WHEREAS RDI is an international non-governmental organisation, based in Paris, France, bringing together national and regional rare disease patient alliances from around the world as well as international rare disease-specific federations to be the global alliance of rare disease patients and families of all nationalities across all rare diseases. RDI's mission is to be a strong common voice on behalf of the 300 million people living with a rare disease around the world. RDI advocates for rare diseases as an international public health priority and represents the interest of people living with a rare disease worldwide; and

WHEREAS WHO and RDI (hereinafter each referred to as a "Party", and together, the "Parties") wish to enter into this Memorandum of Understanding to set forth the terms of which they plan to collaborate on activities relating to impeove the health and well-being of people living with a rare disease worldwide;

Now, therefore, the Parties decide as follows:

Article 1
Objective and Areas of Cooperation

1. Pursuant to the WHO General Programme of Work 2019-2023 (GPW13), and its strategic priorities to promote healthier populations and to serve the most vulnerable, the objective of this Memorandum of Understanding is to assist in addressing public health issues related to rare diseases, to ensure that in the global thrive to achieve Universal Health Coverage, no one is left behind, including regarding the ambitions to:

a. Increase awareness of rare diseases and their visibility in healthcare systems;

b. Strengthen healthcare systems, including improving access to accurate diagnosis, prevention of co-morbidity, and promotion of multidisciplinary holistic care;

c. Improve access to affordable and quality treatments and care; and

d. Encourage Member states to adopt strategies to address rare diseases challenges at

1

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Collaborations

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RDI-IFPMA Round Table on Access

First Round Table on Access to rare disease therapies in LMICs to explore barriers to access, discuss opportunities to overcome these challenges and identify what factors have helped to address them

- Co-organised with the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA)
- International Union for Cancer Control, Geneva, December 4, 2019
- 15 patient representatives
- 14 company representatives from the biopharmaceutical industry

Patient advocates from **Mexico, Guatemala, Uganda, Malaysia, US, UK, France, Cyprus and Portugal** from disease areas including**: haemophilia, SMA, thalassemia, rare cancers, Gaucher and other lysosomal storage disorders**, described the expanded programmes that exist for their diseases at international level and more specifically about how they are carried out in their countries and the obstacles they encounter on the ground.

IFPMA

RARE DISEASES INTERNATIONAL

NGO Committee for Rare Diseases

- Promotes 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)

- RDI is a member and has a seat on the executive board

- RDI contributed to UN submissions and statements on:
  - The right to health and SDGs
  - The right of people living with disability

- RDI co-organised NGO Committee 2nd high level meeting in Feburary 2019

- RDI 5th Membership Meeting organised back to back in New York

NGO COMMITTEE FOR
RARE DISEASES

RARE DISEASES INTERNATIONAL

Global Commission

- High-level expert panel led by Takeda, Microsoft and EURORDIS
- Purpose is to build road map to improve diagnostic pathways for children with rare diseases
- Four RDI Members in the Commission: Yann Le Cam (EURORDIS), Durhane Wong-Rieger (CORD Canada), Kevin Huang (CORD China), Pamela Gavin (NORD)
- Involve RDI members through consultations on recommendations
- RDI participated in the launch and promotion of the recommendations and pilots in February 2019

GLOBAL COMMISSION

to End the Diagnostic Odyssey for Children with a Rare Disease

International Rare Disease Research Consortium

- Unites national and international governmental and non-profit funding bodies, companies, umbrella patient advocacy organizations, and scientific researchers to promote international collaboration and advance rare diseases research worldwide

- RDI in IRDiRC's Consortium Assembly and Patient Advocates Constituency Committee (PACC).
- 13 of the 15 members organisations on the Patient Advocates Constituent Committee are RDI members
- Ritu Jain represented RDI
  - IRDiRC Meeting, Leiden, Netherlands , May 22-23
  - IRDiRC Meeting, Paris, France, November 21-22

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APEC Rare Disease Network

Asia-Pacific Economic Cooperation

In 2019 RDI and its members participated in:

- APEC Rare Disease Policy Dialogue focused on Latin America, Santiago, Chile, July 10-11
- APEC Workshop ‘Using APEC Rare Disease Framework to develop National and Local Action’, Taipei, Taiwan, October 21

back to back to APARDO Summit and Taiwan Foundation for Rare Disorders 20th Anniversary celebrations.

Financial Report

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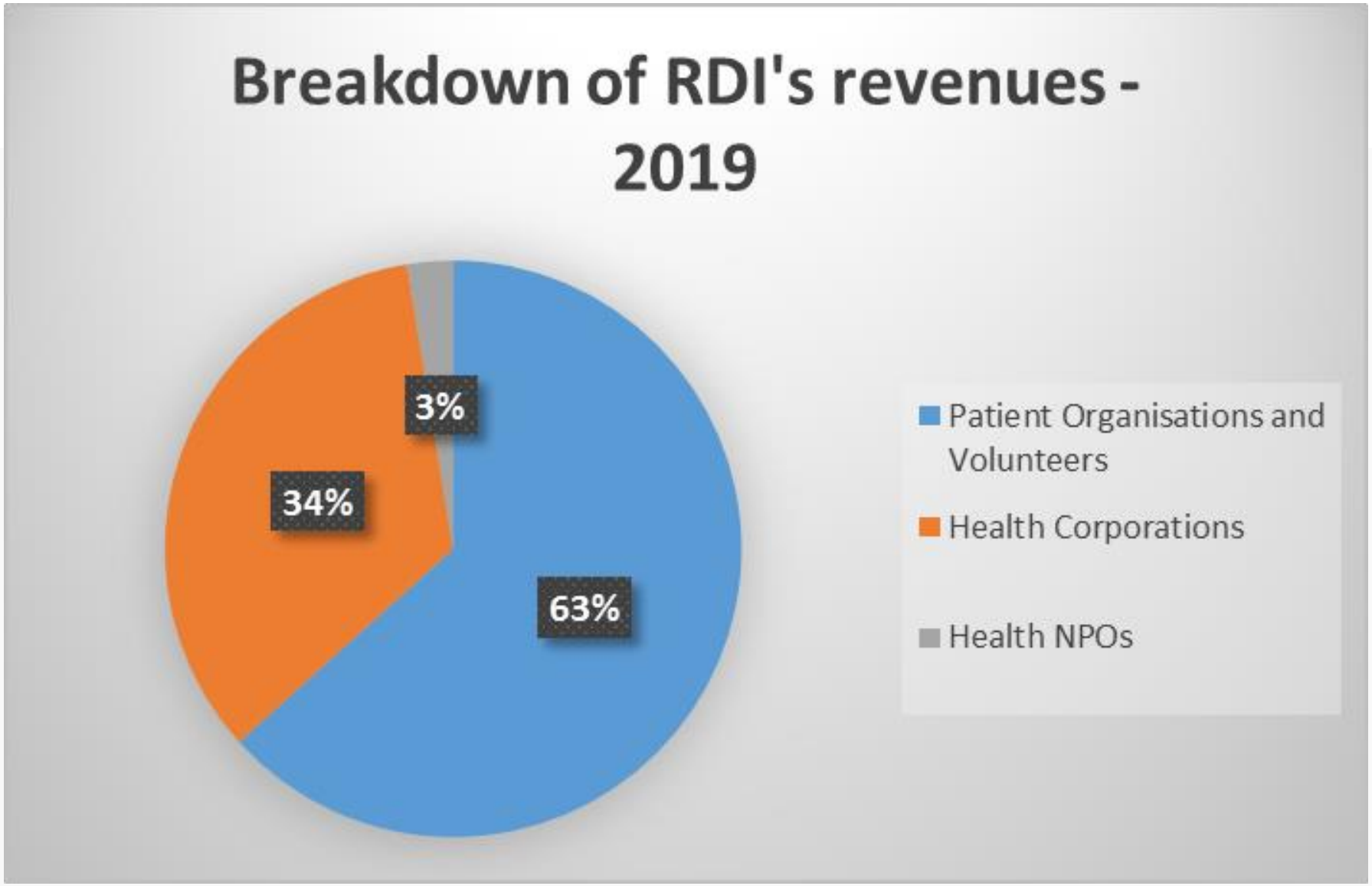
RARE DISEASES INTERNATIONAL

2019 Financial report VS 2019 budget

(Profit and Loss including in kind contributions)

Revenue	Budget	Actual	Ratio	Δ in euros	Δ in %
Patient Organisations	**225 750**	**227 876**	**39%**	**2 126**	**1%**
In kind contributions (EURORDIS)	219 750	227 076	39%	7 326	3%
Membership fees	6 000	800	0%	-5 200	-87%
Individuals	**103 090**	**143 195**	**24%**	**40 105**	**39%**
Volunteers	103 090	143 195	24%	40 105	39%
Donations					
Corporates	**265 000**	**200 000**	**34%**	**-65 000**	**-25%**
Pharma. and Biotech Companies	265 000	200 000	34%	-65 000	-25%
Other Health Sector Corporates					
Outside Health Sector Corporates					
Not for Profit Organisations		**15 000**	**3%**	**15 000**	
Pharma. and Biotech Found.		15 000	3%	15 000	
Other Health Sector NPOs					
Outside Health Sector NPOs					
Event Fees					
Miscellaneous					
Reimbursement					
Others					
Sub-total	**593 840**	**586 071**	**100%**	**-7 769**	**-1%**
Recovery of provisions					
Report of non-used income					
Total Revenue	**593 840**	**586 071**		**-7 769**	**-1%**

Expenses	Budget	Actual	Ratio	Δ in euros	Δ in %
Staff	**158 000**	**110 574**	**27%**	**-47 426**	**-30%**
Wages and charges	158 000	110 574	27%	-47 426	-30%
Other salaries					
Training and other costs					
Volunteers	**103 090**	**143 195**	**17%**	**40 105**	**39%**
Representatives and task forces	103 090	132 470	17%	29 380	28%
Projects, office and translators		10 725		10 725	
Logistics	**144 650**	**106 094**	**24%**	**-38 556**	**-27%**
Travels and subsistence	144 650	97 337	24%	-47 313	-33%
Event logistics and catering		8 757		8 757	
Services	**84 000**	**124 160**	**14%**	**40 160**	**48%**
Fees	46 500	60 217	8%	13 717	29%
Partners	20 000	20 000			
Telecom and post	1 500	1 620	0%	120	8%
Rent	15 000	41 235	3%	26 235	175%
Other services	1 000	1 088	0%	88	9%
Purchase	**6 000**	**6 683**	**1%**	**683**	**11%**
Office furniture	500	116	0%	-384	-77%
Amortisation					
Communications, Publications	5 000	6 427	1%	1 427	29%
Other purchases	500	140	0%	-360	-72%
Miscellaneous	**98 100**	**77 437**	**17%**	**-20 663**	**-21%**
Financial expenses, Insurance, Tax	3 350	2 171	1%	-1 179	-35%
In kind overheads	94 750	75 267		-19 483	
Exceptional expenses					
Sub-total	**593 840**	**568 144**	**100%**	**-25 696**	**-4%**
Contingency and loss provisions					
Commitment on assigned income					
Total Expenses	**593 840**	**568 144**		**-25 696**	**-4%**
Result		**17 927**			


Breakdown of RDI's revenues - 2019
3%
34%
63%
Patient Organisations and Volunteers
Health Corporations
Health NPOs

Thank you!