

WHO Support for Rare Diseases

*Durhane Wong-Rieger, PhD
Immediate Past Chair, International Alliance of Patients
Organizations*

Rare Disease International Launch Meeting
28 May 2015



International Alliance of
Patients' Organizations

A global voice for patients

Who is the WHO?

- The World Health Organization (WHO) is a specialized agency of the United Nations (UN) concerned with international public health.
 - WHO's membership is made up of 194 countries, known as Member States, and two Associate Members.
 - WHO meets every year in May at the World Health Assembly (WHA), the decision-making body of WHO. WHO is overseen by a Director-General who is elected every five years by the Health Assembly.
 - Their work is supported by the 34 Members of the Executive Board who are elected by the Health Assembly and meet twice a year in January and May. The main function of the Board is to put into effect the decisions and policies of the Health Assembly.
 - WHO employs a secretariat of over 8,000 people from all over the world, who work for WHO in 147 country offices, six regional offices and at the headquarters in Geneva, Switzerland.

WHO Role in Public Health

- Providing leadership on matters critical to health and engaging in partnerships where joint action is needed;
- Shaping the research agenda and stimulating the generation, translation and dissemination of valuable knowledge;
- Setting norms and standards and promoting and monitoring their implementation;
- Articulating ethical and evidence-based policy options;
- Providing technical support, catalyzing change, and building sustainable institutional capacity; and
- Monitoring the health situation and assessing health trends.

WHO Priority Areas (2013-2014)

- Communicable diseases:
 - Reduce "health, social and economic burden" of communicable diseases in general
 - Combat HIV/AIDS, malaria and tuberculosis
- Noncommunicable diseases:
 - Reduce "disease, disability and premature deaths from chronic NCDs, mental disorders, violence, injuries, visual impairment
 - Surgical safety
- Life course and life style
 - reduce morbidity, mortality and improve health during key stages, i.e., pregnancy, childbirth, neonatal, childhood and adolescence, and improve sexual and reproductive health and promote active and healthy aging for all individuals

WHO Priority Areas (2013-2014)

- Emergency work (coordinate with Member States)
 - Reduce avoidable loss of life, burden of disease and disability
 - Declared spread of polio is world health emergency
 - Declared spread of Ebola is a public health emergency
- Health Policy: Address social and economic determinants and promote healthier environments
 - Develop and promote evidence-based tools, norms, standards
 - Improve health services governance, financing, staffing, and management
 - Improve availability and quality of evidence and research to guide policy making
 - ensure improved access, quality and use of medical products and technologies

WHO Priority Areas (2013-2014)

- WHO Functioning
 - Provide leadership, strengthen governance and foster partnership and collaboration with countries, the United Nations system, and other stakeholders in order to fulfill the mandate of WHO in advancing the global health
 - Develop and sustain WHO as a flexible, learning organization
- PARTNERSHIPS
 - WHO and World Bank manage International Health Partnership
 - WHO runs the Alliance for Health Policy and Systems Research
- Global Public Health Campaigns
 - World Tuberculosis Day, World Immunization Week, World Malaria Day, World No Tobacco Day, World Blood Donor Day, World Hepatitis Day, and World AIDS Day

Benefits for Patient Organizations of Working with WHO

- Raise awareness of a health issue
- Develop research statistics and evidence base to support advocacy campaigns
- Joint activities between POs and WHO, e.g.,
 - Gain recognition for a global health issue (HCV)
 - Produce joint publication at international level (dementia, multiple sclerosis)
 - Prevention/treatment programme at country or regional level (NCDs)

Pathways for Working with WHO

- Work through one or more priority clusters
 - NCDs and mental health; Health security and environment, Health action in crises, Innovation, information, evidence and research, General management, HIV/AIDS, TB, malaria, and neglected tropical diseases, Health systems and services, Family and community health
- Civil Society Initiative
- Member State Support
 - National Ministries of Health to put WHO policy into action
 - Get support of Member States
- WHO Regional and Country Offices/Regional Committees

Official Relations with WHO

Criteria for NGO Official Relations: represent a substantial proportion of people globally in the relevant area of interest

Key Steps

1. Build a relationship with a programme through exchanging information and reciprocal participation in meetings
2. Identify joint activities which utilise expertise of the NGO
3. Collaborations agreed in writing with details of activities which may result in a period of working relations
4. After two years, organization can apply for admission into official relations with WHO

Case Study: World Hepatitis Alliance

- World Hepatitis Alliance: global voice for 500 million people living with chronic viral hepatitis
 - Goal: Eradicate HBV and HCV through better awareness, prevention, care, support and access to treatment,
- 2007: Established World Hepatitis Day (19 May)
 - Unofficial so challenging to get countries to adopt
 - Recognition: Need recognition by WHO and official recognition
- 2009: Four Member States proposed resolution to recognize hepatitis at Executive Board meeting; debated

Case Study: World Hepatitis Alliance

- January 2010: With aid of IAPO (which is in official relations) WHA introduced resolution on viral hepatitis to Executive Board; accepted
- May 2010: World Hepatitis Alliance, through IAPO, made intervention at World Health Assembly; adopted
 - Acknowledges viral hepatitis as serious global public health issue
 - Establishes official World Hepatitis Day on 28 July each year
 - Requires WHO to develop global prevention & control strategy
- WHO supports affordable access to new HCV therapy (Solvadi) for patients in Low and Middle Income Countries
 - Debate on tiered pricing
 - Gilead makes “licensing deal” for generic companies to make lower cost versions for 91 developing nations

WHO Role in Rare Disease

- Possible roles/contributions of WHO re: rare diseases
 - Support for a universal definition of rare disease
 - Acknowledge rare diseases as global public health issue
 - Support international classification for rare diseases
 - Call for innovation, information, research, and treatment
 - Inclusion of “drugs for rare diseases” as essential medicines
 - Facilitate establishment of international Centers of Reference/Expertise