

# WFH GAP PROGRAM: A MODEL FOR RESPONDING TO A GLOBAL RARE DISEASE

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**WFH**

WORLD FEDERATION OF HEMOPHILIA  
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA

# THE CHALLENGES OF A GLOBAL RARE DISEASE

## GLOBAL REALITY in 2002

- 75% PWH not diagnosed
- Many die in childhood
- Hemophilia NOT a priority with Governments, although treatment is very successful
- Lack of infrastructure, training, education
- Cost of treatment prohibitive for individuals

## THE GAP

- Significant **gap** between expected number of people with hemophilia (PWH) and known cases
- **Gap** between existing and potential quality of hemophilia care

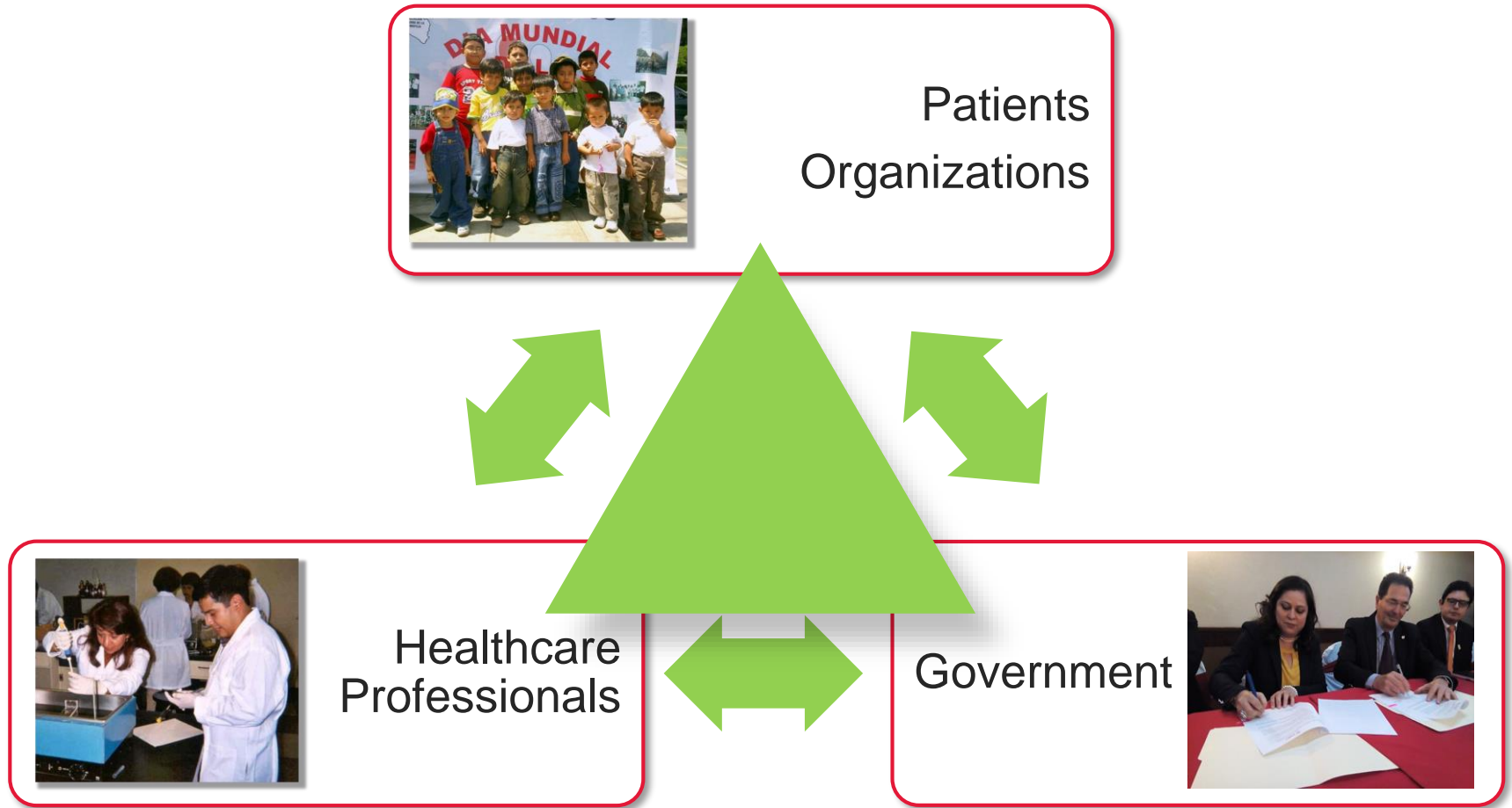
# GLOBAL ALLIANCE FOR PROGRESS (GAP) PROGRAM — BRINGING TREATMENT TO ALL

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- **Healthcare development program** launched on World Hemophilia Day 2003
- **Foster partnership** between government, healthcare professionals and patients
- Develop **sustainable national care programs**
- To **close the gap** between the:
  - estimated and actual number of people known with bleeding disorders
  - amount of treatment products needed versus that available
  - number of people born with hemophilia and the number who reach adulthood



# AN INTEGRATED APPROACH



Multi-year (sustainability) Commitment by all stakeholders

# WFH DEVELOPMENT MODEL

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Successful programs work simultaneously to improve all aspects of care development



Achieve government support through advocacy



Improve care delivery



Improve medical expertise and increase accurate laboratory diagnosis through training



Increase access to safe treatment products



Build a strong national patient organization through capacity



Track national demographic data



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# OVER 16 YEARS OF DEMONSTRABLE CHANGE AND MEASURABLE OUTCOMES (2003-2018)

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31,373 new patients with hemophilia, 5,360 patients with von Willebrand Disease, and 3,819 patients with rare clotting factor deficiencies identified



17,853 patients, family members, and national member organization (NMO) board members received training



12,564 hemophilia team members and regulators trained  
14,186 healthcare professionals acquired a general awareness of hemophilia



25 national care programs established in 31 GAP countries



6,185 billion IUs cumulative increase in product supply (treatment purchased)

**THANK YOU**



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