WFH GAP PROGRAM: A MODEL FOR RESPONDING TO 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

• 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

Patients Organizations

Healthcare Professionals

Government

Multi-year (sustainability) Commitment by all stakeholders
WFH DEVELOPMENT MODEL

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

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