World Federation of Hemophilia
Steps for Developing National Hemophilia Care Programs

Objectives

- To obtain government support for national hemophilia care program within the health system
- To set up a national hemophilia care program (national plan defined with key treaters and NMO).
- To make the organization of hemophilia treatment more efficient.
- To provide accurate diagnosis and appropriate treatment.
- To obtain the best quality blood products in sufficient quantity at an affordable cost.
- Develop and improve regulatory knowledge.
- To develop a strong patient organization for advocacy and education.
- To set good and efficient data collection system within health services with contribution of all key players.
- To develop the ability to track and report patient health outcomes through surveillance, enhanced data collection and outcome analysis.
- To conduct basic descriptive studies on bleeding disorders.

Development Steps

1. No government support or interest in hemophilia care.
3. Some level of government involvement in hemophilia care (e.g. hemophilia committee or task force).
4. Limited central or regional government resources allocated for hemophilia care.
5. Official government commitment to hemophilia care.
7. Hemophilia is a line item in a country’s annual healthcare budget.
8. Government is a key partner in sustainable national hemophilia care program.

Laboratory Diagnosis

- Isolated doctor in major city works with no resources.
- Basic treatment is possible in hospital(s) in major city.
- Regular hematology outpatient clinic with follow-up offered.
- Creation of a core team within hospital that forms the basis of a full hemophilia treatment centre (HTC).
- Core team within hospital (HTC) has a medical patient registry & treatment guidelines/protocols.
- Additional hemophilia treatment centres with core teams for children and/or adults in major cities.
- Coordinated network of designated HTC’s with national treatment protocols.
- Full comprehensive hemophilia care team is formed in the major HTC(s).
- Basic teams formed in other areas/regions.
- Established sustainable national hemophilia care program.

Medical Treatment

- Basic medical laboratory diagnostic ability.
- Basic screening tests (bleeding time, platelet count, coagulation test).
- Doctor specialized in hematology.
- Hematologist(s) assigned to hemophilia care.
- Key hematologist(s) assigned to hemophilia care.
- Specialized hemophilia core team (hematologist, nurse, physiotherapist, orthopedist, lab technologist).
- Education provided to patients.
- Home care available for patients.
- Specialized comprehensive care team (social worker, dentist, psychologist, infectious diseases specialist, genetic counsellor).
- Education offered to general medical community.

Treatment Products

- Local production of:
  a. Whole blood
  b. Plasma
  c. Fresh frozen plasma (FFP)
  d. Cryoprecipitate
  e. Cryo-dried cryoprecipitate
  2. Combination of local production of cryo and/or FFP and some purchase of plasma-derived factor concentrates:
  a. Less than 2 IU per capita of concentrates
  b. Between .2 and .5 IU
  c. Between 5 and 1 IU
  d. Between 1 and 2 IU
  3. Proper national tender system in place
  4. Examine feasibility of contract fractionation of plasma-derived concentrates
  5. Examine feasibility of local fractionation of plasma-derived concentrates
  6. Purchase of plasma-derived concentrates (>2 IU per capita)
  7. Examine feasibility of combined purchase of plasma-derived and recombinant concentrates

Patient Organization

- Organization formed by a nucleus of patients
- Organization structured, recognized/registered with a constitution.
- Organization holds regular meetings with a core group of volunteers and educates patients and families in major city.
- NMO patient registry.
- Organizes activities including:
  a. Educational services
  b. Fundraising
  c. Training
  d. Membership
  e. Volunteer recruitment
  f. Advocacy

Data Collection and Outcomes Research

- Basic registry of all patients with bleeding disorders
- Registry of all identified patients with bleeding disorders based on accurate diagnosis and detailed medical information
- Ministry of Health central registry with mandatory reporting and real-time data entry
- Collate and analyze information on Quality of Life (QoL) for people with bleeding disorders
- Design and conduct observational studies on bleeding disorders
- Participate in multi-national / multi-center comparative research on people with bleeding disorders

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* Development steps do not necessarily denote chronological order. Situations may vary.