

## World Federation of Hemophilia Steps for Developing National Hemophilia Care Programs

Government Support	Care Delivery	Medical Expertise		Treatment Products	Patient Organization	Data Collection and Outcomes Research
<b>Objectives</b>						
<ul style="list-style-type: none"> <li>To obtain government support for national hemophilia care program within the health system</li> </ul>	<ul style="list-style-type: none"> <li>To set up a national hemophilia care program (national plan defined with key treaters and NMO).</li> <li>To make the organization of hemophilia treatment more efficient.</li> </ul>	<ul style="list-style-type: none"> <li>To provide accurate diagnosis and appropriate treatment.</li> </ul>		<ul style="list-style-type: none"> <li>To obtain the best quality blood products in sufficient quantity at an affordable cost.</li> <li>Develop and improve regulatory knowledge</li> </ul>	<ul style="list-style-type: none"> <li>To develop a strong patient organization for advocacy and education.</li> </ul>	<ul style="list-style-type: none"> <li>To set good and efficient data collection system within health services with contribution of all key players</li> <li>To develop the ability to track and report patient health outcomes through surveillance, enhanced data collection and outcome analysis</li> <li>To conduct basic descriptive studies on bleeding disorders</li> </ul>
<b>Development Steps</b>						
<ol style="list-style-type: none"> <li>No government support or interest in hemophilia care.</li> <li>Government recognition of main HTC as a reference centre.</li> <li>Some level of government involvement in hemophilia care (e.g. hemophilia committee or task force).</li> <li>Limited central or regional government resources allocated for hemophilia care.</li> <li>Official government commitment to hemophilia care.</li> <li>Government contributes substantial financial support for hemophilia care.</li> <li>Hemophilia is a line item in a country's annual healthcare budget.</li> <li>Government is a key partner in sustainable national hemophilia care program.</li> </ol>	<ol style="list-style-type: none"> <li>Isolated doctor in major city works with no resources.</li> <li>Basic treatment is possible in hospital(s) in major city</li> <li>Regular hematology outpatient clinic with follow-up offered</li> <li>Creation of a core team within hospital that forms the basis of a full hemophilia treatment centre (HTC)</li> <li>Core team within hospital (HTC) has a medical patient registry &amp; treatment guidelines/ protocols</li> <li>Additional hemophilia treatment centres with core teams for children and/or adults in major cities.</li> <li>Coordinated network of designated HTCs with national treatment protocols.</li> <li>Full comprehensive hemophilia care team is formed in the major HTC(s)</li> <li>Basic teams formed in other areas/regions</li> <li>Established sustainable national hemophilia care program.</li> </ol>	<p><b>Laboratory Diagnosis</b></p> <ol style="list-style-type: none"> <li>Basic laboratory diagnostic ability</li> <li>Basic screening tests (bleeding time, platelet count, coagulation test)               <ol style="list-style-type: none"> <li>PT</li> <li>APTT</li> <li>TT</li> </ol> </li> <li>Internal Quality Control</li> <li>Factor Assays</li> <li>Participation in EQAS</li> <li>VWD Assays and Inhibitor detection</li> <li>Molecular genetic detection/DNA mutation detection and carrier detection/pre-natal diagnosis</li> </ol>	<p><b>Medical Treatment</b></p> <ol style="list-style-type: none"> <li>Basic medical knowledge in hematology (includes pediatricians and general practitioners)</li> <li>Doctor specialized in hematology</li> <li>Hematologist(s) assigned to hemophilia care</li> <li>Key hematologist(s) trained in hemophilia</li> <li>Specialized hemophilia core team (hematologist, nurse, physiotherapist, orthopedist, lab technologist)</li> <li>Education provided to patients</li> <li>Home care available for patients</li> <li>Specialized comprehensive care team (social worker, dentist, psychologist, infectious diseases specialist, genetic counsellor)</li> <li>Education offered to general medical community.</li> </ol>	<ol style="list-style-type: none"> <li>Local production of:               <ol style="list-style-type: none"> <li>Whole blood</li> <li>Plasma</li> <li>Fresh frozen plasma (FFP)</li> <li>Cryoprecipitate</li> <li>Freeze-dried cryoprecipitate</li> </ol> </li> <li>Combination of local production of cryo and/or FFP and some purchase of plasma-derived factor concentrates:               <ol style="list-style-type: none"> <li>Less than .2 IU per capita of concentrates</li> <li>Between .2 and .5 IU</li> <li>Between .5 and 1 IU</li> <li>Between 1 and 2 IU</li> </ol> </li> <li>Proper national tender system in place</li> <li>Examine feasibility of contract fractionation of plasma-derived concentrates</li> <li>Examine feasibility of local fractionation of plasma-derived concentrates</li> <li>Purchase of plasma-derived concentrates (&gt;2 IU per capita)</li> <li>Examine feasibility of combined purchase of plasma-derived and recombinant concentrates</li> </ol>	<ol style="list-style-type: none"> <li>Organization formed by a nucleus of patients</li> <li>Organization structured, recognized/registered with a constitution.</li> <li>Organization holds regular meetings with a core group of volunteers and educates patients and families in major city.</li> <li>NMO patient registry.</li> <li>Organizes activities including:               <ol style="list-style-type: none"> <li>educational services</li> <li>fundraising</li> <li>training</li> <li>membership</li> <li>volunteer recruitment</li> <li>advocacy</li> <li>budgeting</li> </ol> </li> <li>Outreach to other regions of the country to identify new patients</li> <li>Regional chapters are formed</li> <li>National organization follows a strategic plan</li> <li>National organization is a partner in national hemophilia care program</li> </ol>	<ol style="list-style-type: none"> <li>No demographic data on people with bleeding disorders</li> <li>Data collected by doctors at some hospitals and/or patient organizations</li> <li>Basic registry of all patients with hemophilia in hospitals or patient organization</li> <li>Basic registry of all patients with bleeding disorders in hospitals or patient organization</li> <li>Registry of all identified patients with bleeding disorders based on accurate diagnosis and detailed medical information</li> <li>Ministry of Health central registry with mandatory reporting and real-time data entry</li> <li>Collate and analyze information on Quality of Life (QoL) for people with bleeding disorders</li> <li>Design and conduct observational studies on bleeding disorders</li> <li>Participate in multi-national / multi-center comparative research on people with bleeding disorders</li> </ol>