WORLD FEDERATION OF HEMOPHILIA

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Senior Public Policy Officer
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Treatment for All

The World Federation of Hemophilia improves and sustains care for people with inherited bleeding disorders around the world.
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Founded in 1963
Recognized by the WHO in 1969

134 national member organizations
GLOBAL ALLIANCE FOR PROGRESS (GAP)

- **Flagship** WFH healthcare development project
- Launched in 2003
- Foster **partnership** between government, healthcare providers and patients
- Develop **sustainable** national care programs
- **Multi-sponsored** program
GLOBAL ALLIANCE FOR PROGRESS

Government support
Actively involving the government in allocating resources to hemophilia care

Care delivery
Supporting the structure through which hemophilia services are provided in a country through a network of hemophilia treatment centres

Medical expertise and laboratory diagnosis
Ensuring that medical professionals are well trained and patients are accurately diagnosed

Treatment products
Helping to enhance the supply of safe treatment products

Patient organization
Providing coaching on effective management, public relations skills, fundraising, advocacy, and patient education
GLOBAL ALLIANCE FOR PROGRESS

Data Collection & Outcomes Research
Helping to gather evidence needed to make the case for better care
## Prevalence and Incidence Rates of Inherited Bleeding Disorders

<table>
<thead>
<tr>
<th>Type</th>
<th>Prevalence</th>
<th>Incidence Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hemophilia A and B</td>
<td>• 400,000 people&lt;br&gt;• 200,000 severe&lt;br&gt;187,183 known to WFH</td>
<td>• A: 1 in 10,000&lt;br&gt;• B: 1 in 50,000</td>
</tr>
<tr>
<td>Von Willebrand</td>
<td>• 6,000,000 people&lt;br&gt;74,819 know to WFH</td>
<td>• 1 in 1,000</td>
</tr>
<tr>
<td>Very rare bleeding disorders – non FVIII, FIX, VWD</td>
<td>42,360 known to WFH</td>
<td>0.33 to 10 in 1 Million</td>
</tr>
</tbody>
</table>

Source: WFH 2015 Annual Global Survey
WFH ANNUAL GLOBAL SURVEY

FVIII use over time: World, Lower, Middle and Upper Income

Report on the WFH Annual Global Survey 2015
### FACTOR VIII NEEDED FOR APPROPRIATE THERAPY

<table>
<thead>
<tr>
<th>FVIII IU PER CAPITA NEEDED</th>
<th>EXPECTED OUTCOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1</td>
<td>• Shortened life expectancy</td>
</tr>
<tr>
<td>1</td>
<td>• Survival from worse effects</td>
</tr>
</tbody>
</table>
| 2 – 4                     | • Adequate episodic therapy  
                          | • Elective surgery  
                          | • Secondary prophylaxis in target joints |
| 5 - 7                     | • Primary prophylaxis  
                          | • Immune tolerance induction (ITI) |

Evatt, Haemophilia 2002; 8:152
ESTIMATED GLOBAL FVIII USE

Population

- Asia Pacific: 60%
- Africa: 16%
- Europe: 10%
- Latin America and the Caribbean: 9%
- Northern America: 5%

FVIII TOTAL IU

- Asia Pacific: 18%
- Northern America: 32%
- Africa: 2%
- Europe: 34%
- Latin America and the Caribbean: 14%

Source: WFH 2015 Annual Global Survey and Worldometers
USE OF PLASMA AND CRYO

Source: WFH 2015 Annual Global Survey
Use of plasma and cryoprecipitate 2015

Source: WFH 2015 Annual Global Survey
GAP: INCREASE IN IDENTIFIED PWH (2003-2016)

- Philippines - 2003
- Georgia - 2003
- Armenia - 2004
- Thailand - 2004
- Azerbaijan - 2005
- Ecuador - 2007
- Belarus - 2008
- Syria - 2009
- Moldova - 2011
- Morocco - 2012
- Colombia - 2013
- Mexico - 2014
- Serbia - 2015
- Egypt - 2015
- Vietnam - 2016 new
- Turkey - 2016 new

- Total Diagnosed Patients at GAP enrollment - Adjusted
- Total Newly Diagnosed/Registered Patients
GAP: INCREASE IN FACTOR VIII IU PER CAPITA (2003 - 2016)
THANK YOU