

WORLD FEDERATION OF HEMOPHILIA

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London – July 2, 2015



WFH

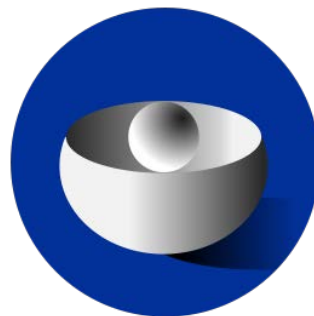
WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

The World Federation of Hemophilia (WFH), an international not-for-profit organization, was established in 1963. It is a global network of patient organizations in 127 countries and has official recognition from the World Health Organization

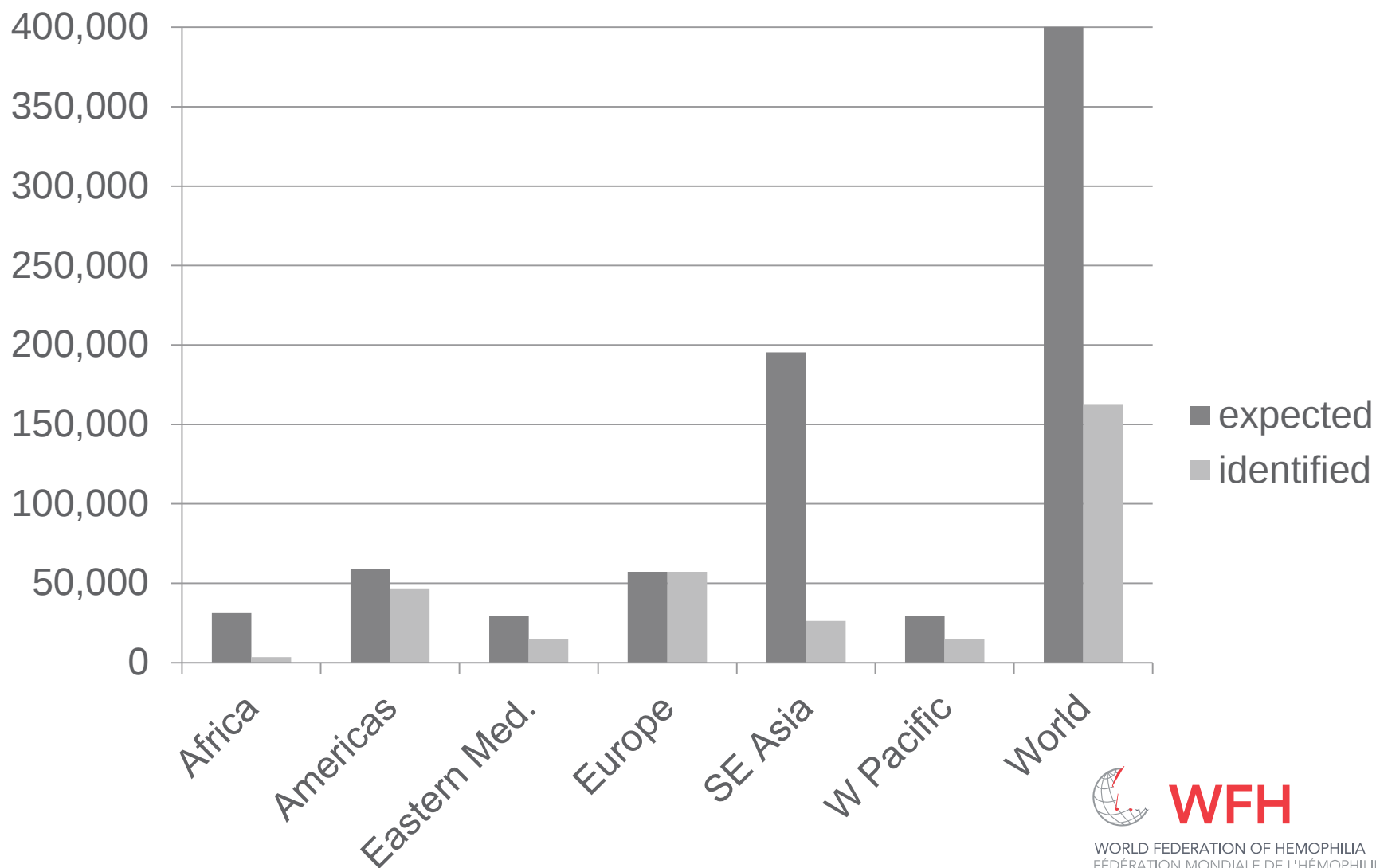
PATIENTS' PERSPECTIVE

Global significance of decisions made by FDA/EMA

- o Humanitarian aid
- o Product withdrawals/recalls
- o Indications
- o How products are used in different parts of the world



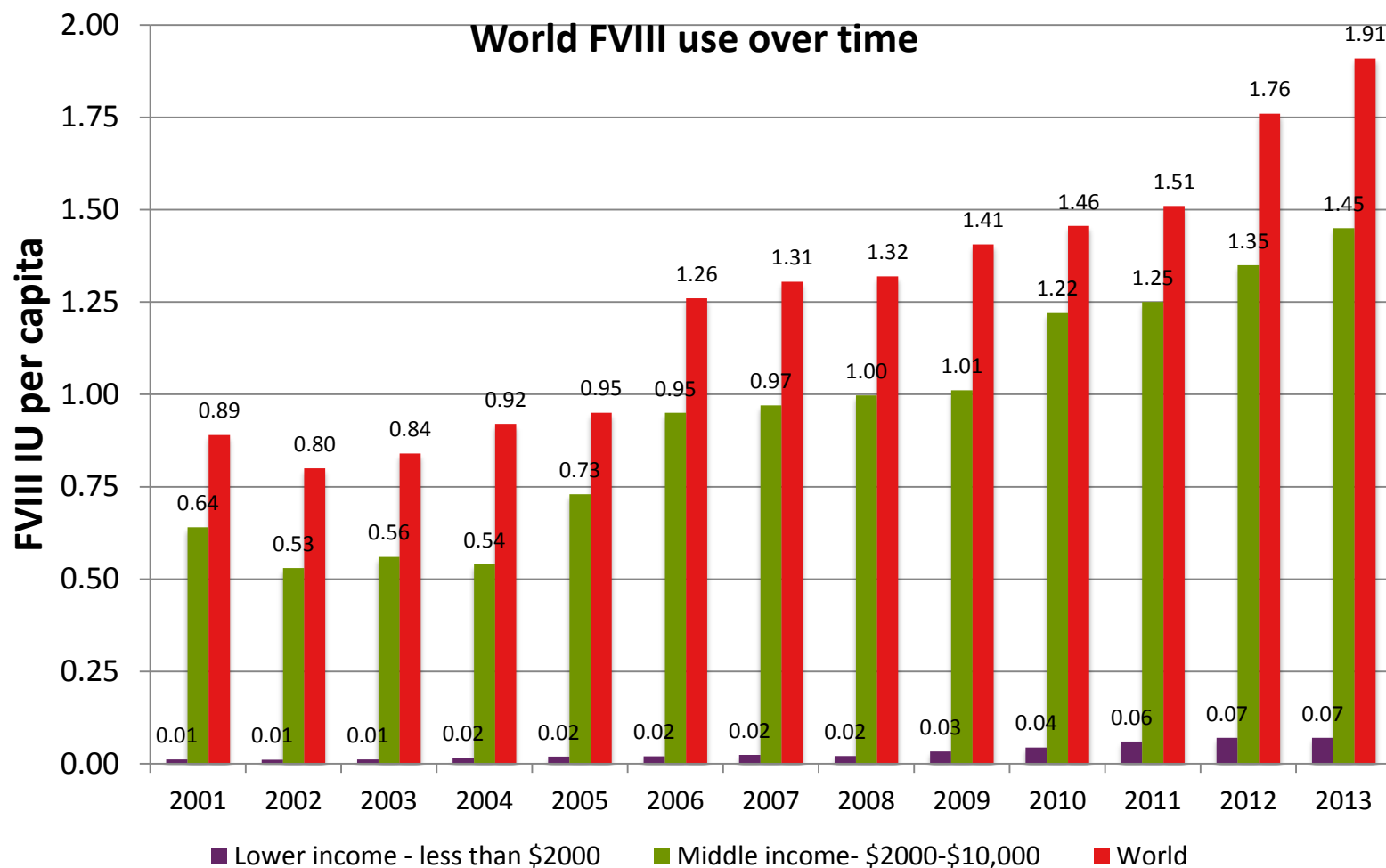
IDENTIFIED PATIENTS – REGION



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INCREASE IN FACTOR USE PER CAPITA



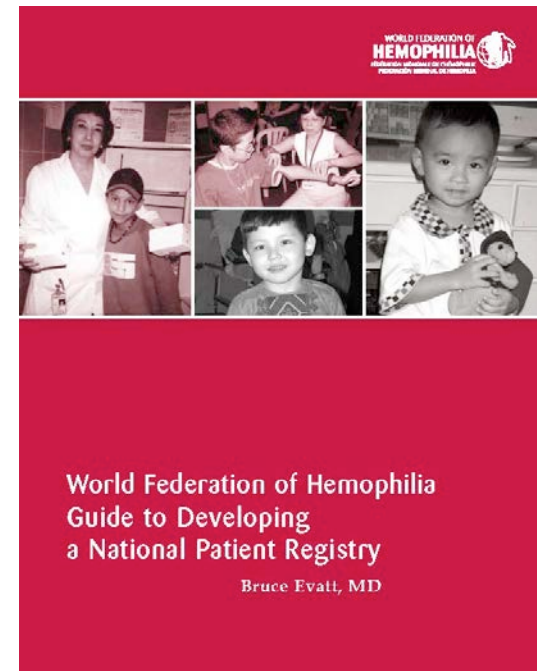
Source: REPORT ON THE ANNUAL GLOBAL SURVEY 2013



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2013 Global Survey: Reported data source

- 107 countries reporting
- Country registry: 31
- Registry of HTC's: 24



55% of new cases – no family history or spontaneous mutation

- Families with a history of hemophilia
- Parents with no experience/knowledge of hemophilia

Transparency vs. data protection laws

- o WFH would like to see more post-marketing surveillance
- o Education on the importance of PMS
- o PUPs (and other patients) enrolled in clinical studies, not in registries?
- o Unique, anonymous identifier for all patients?



THE 9TH WFH GLOBAL FORUM

on Research and
Treatment Products
for Bleeding Disorders

Montreal, Canada
October 22–23, 2015

For more information go to
www.wfh.org/en/globalforum



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THANK YOU



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