

PATIENTS' VIEWS ON INHIBITORS: EXPECTATIONS AND INITIATIVES OF THE WORLD FEDERATION OF HEMOPHILIA

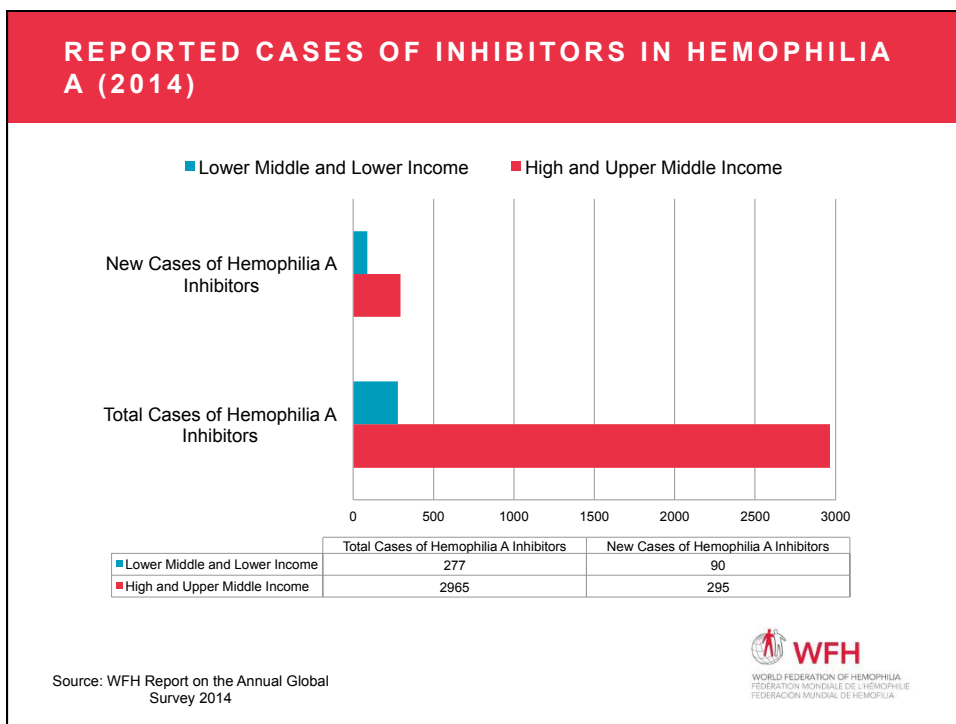
Mark Brooker, Senior Public Policy Officer
Milan · March 5, 2016

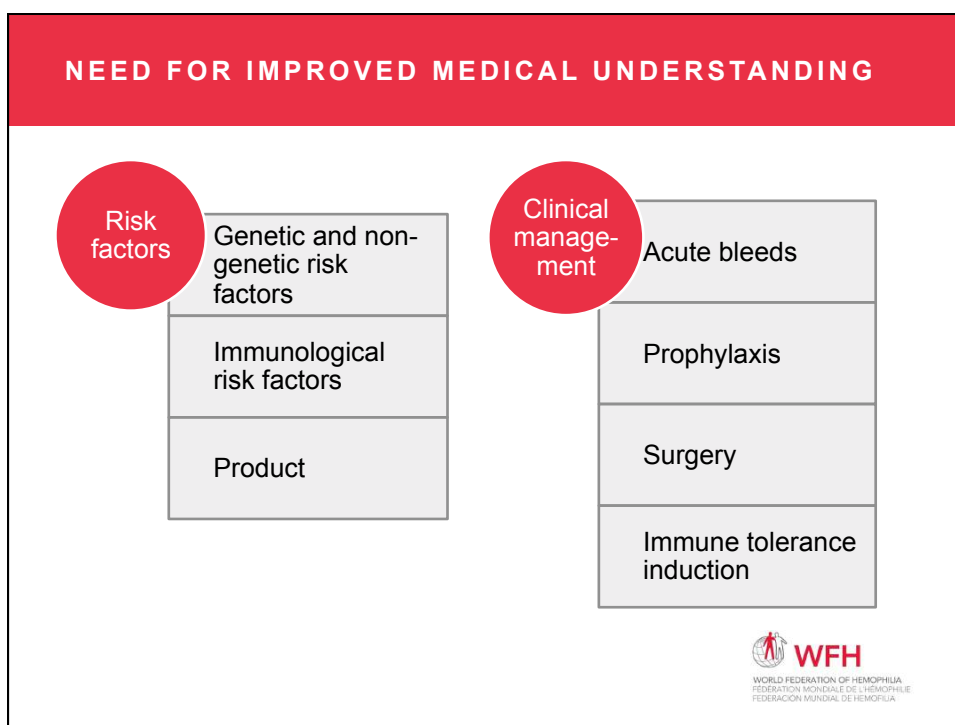
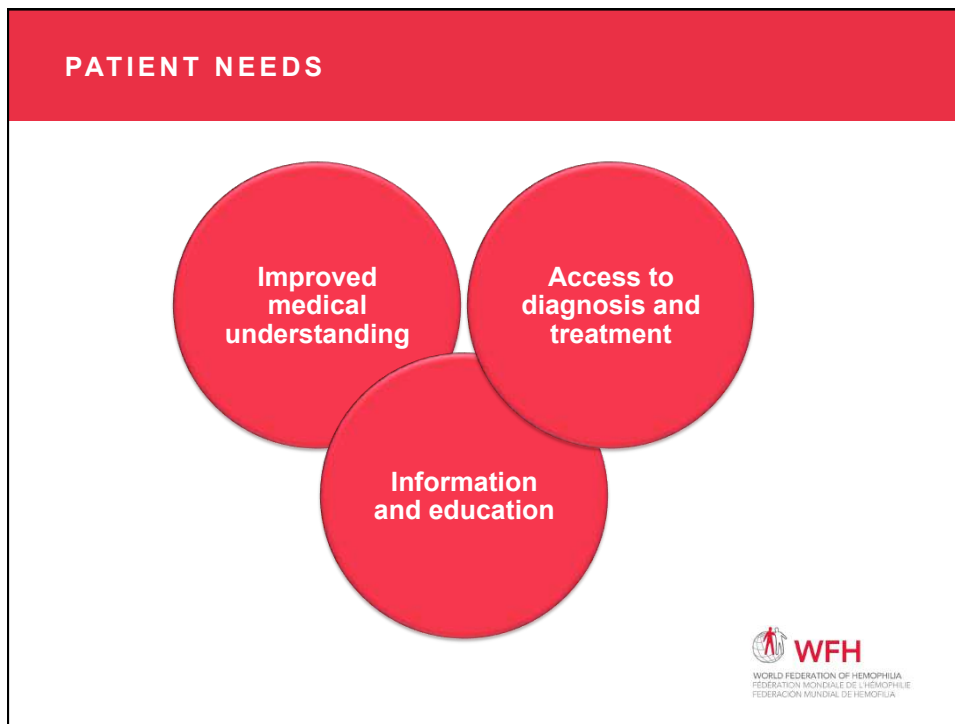


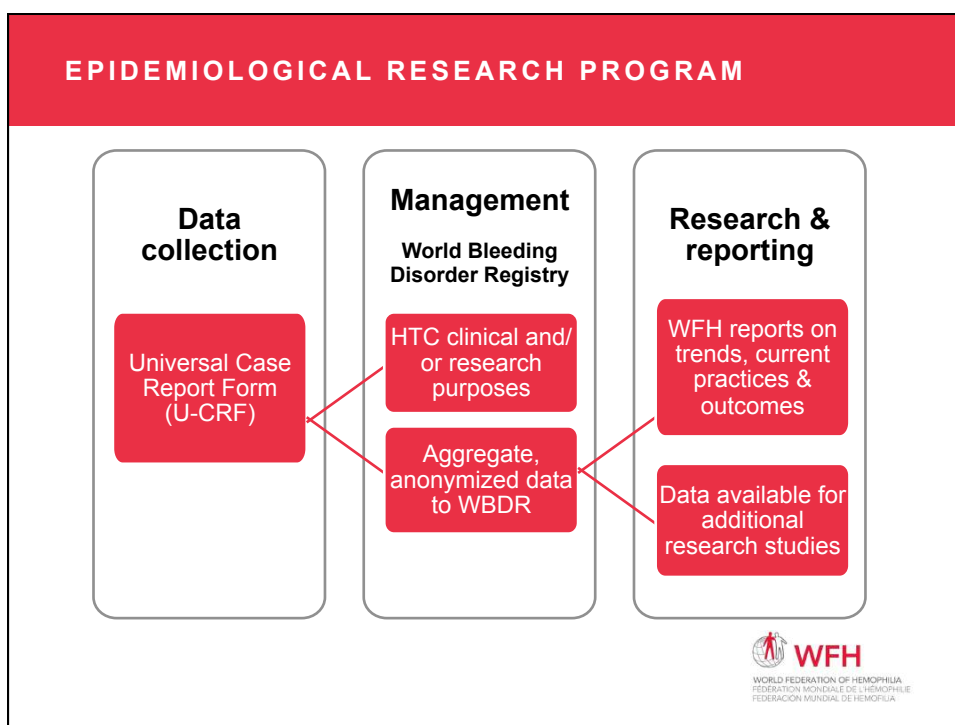
VIEWES OF THE GLOBAL COMMUNITY

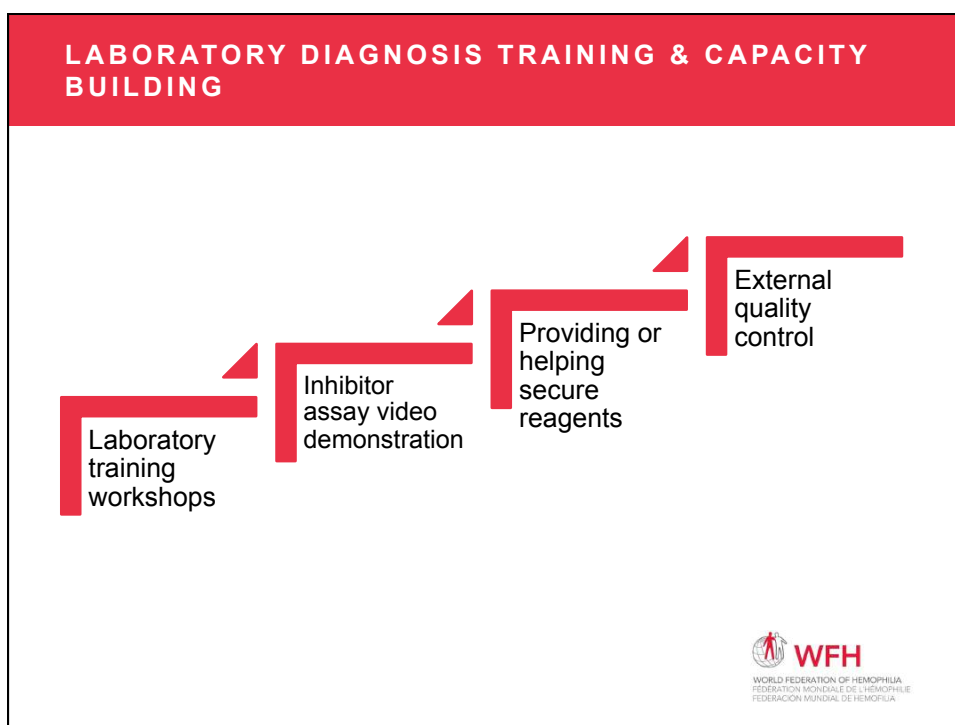
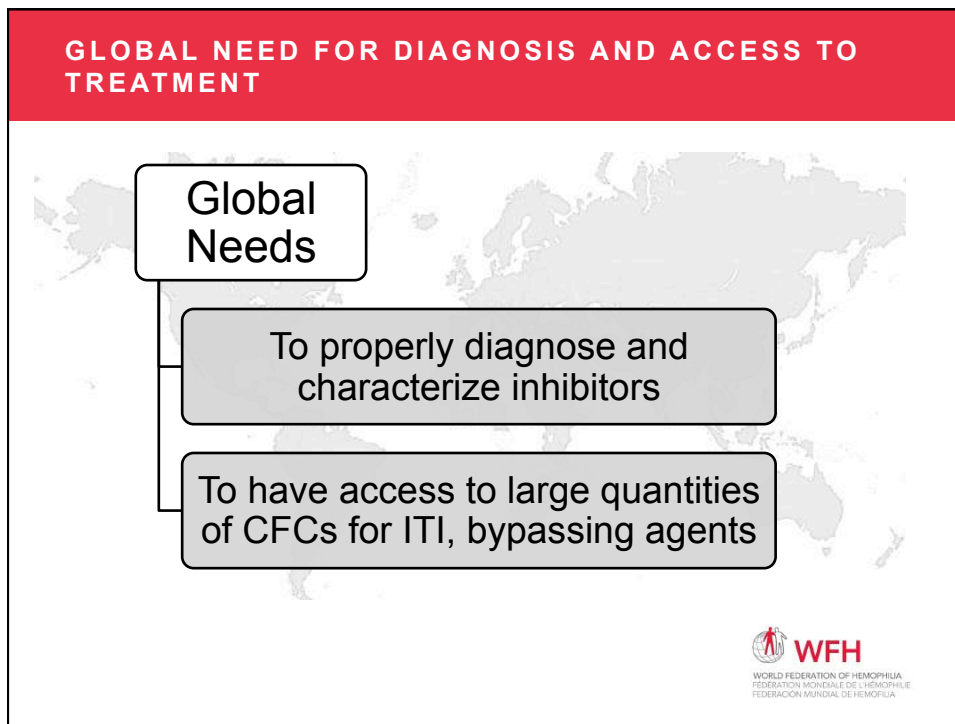
With the exception of lack of access to treatment, we know that inhibitor development is the most significant challenge in hemophilia care












WFH HUMANITARIAN AID PROGRAM


- WFH channels the largest humanitarian aid donations globally
- Channelling over 270 million IUs of CFCs, reaching 87 countries
- Donations sent to Hemophilia Treatment Centres and established Hemophilia Organizations
- WFH expects to channel over 600 million IUs of CFCs over the next 5 years
- Development of an online reporting platform, including information on inhibitors development

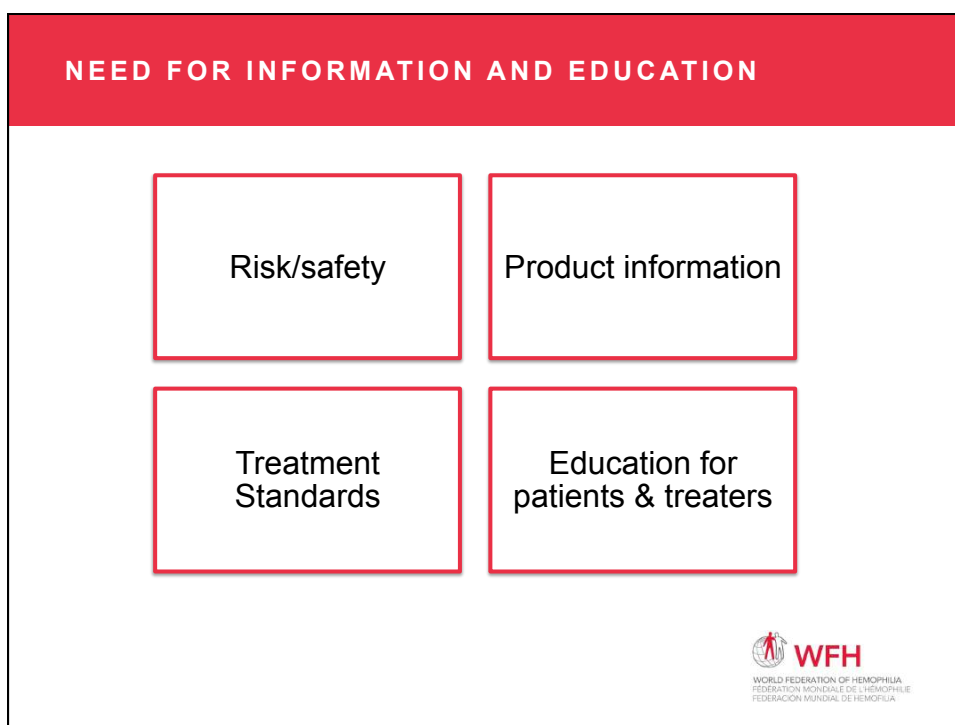
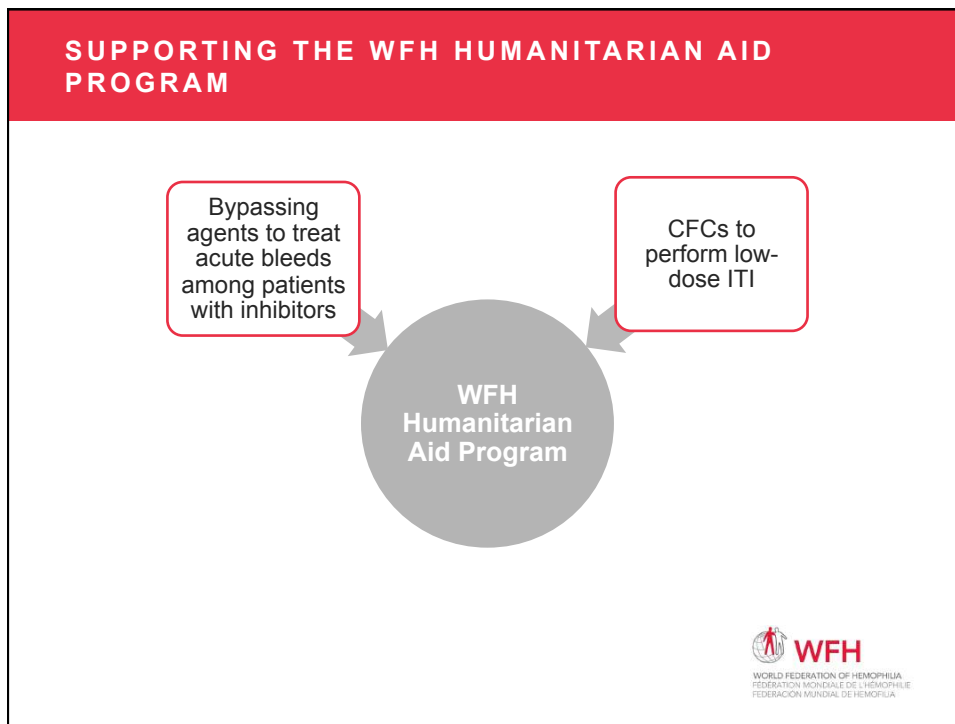


WFH HUMANITARIAN AID PROGRAM

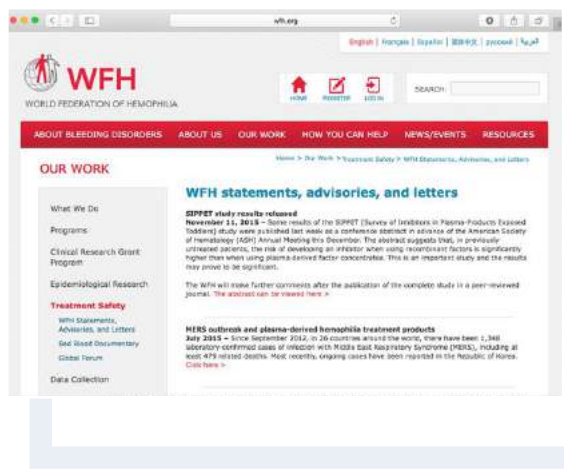
Survey on inhibitors in recipient countries

- Ethical implications of treatment
- Availability/challenges in diagnosis
- Number of patients with inhibitors
- Availability of bypassing agents
- Willingness to start ITI using product donations





GLOBAL SURVEILLANCE




Bring patients, clinicians and regulators together

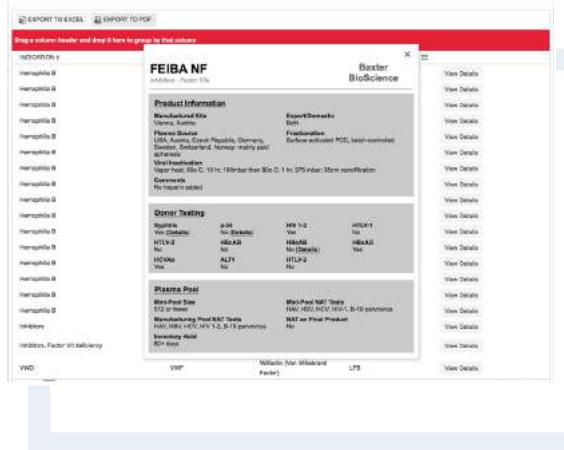
Monitor risk/safety

Keep community protected and informed

Global advocacy



PRODUCT INFORMATION: ONLINE REGISTRY




Online access

Searchable

Real-time updates

Expanded list of indications, products and manufacturers

Pipeline products



EDUCATIONAL RESOURCES FOR PATIENTS AND TREATERS



INHIBITORS

eLearning Centre

The web section is supported by funding from **Baxalta**

WHAT ARE INHIBITORS?
WHO IS AT RISK?
DIAGNOSES
TREATMENT OPTIONS
LEARN MORE

Inhibitors are a serious medical problem that can occur when a person with hemophilia has an immune response to treatment with clotting factor concentrates.

The immune system defends the body from harmful germs and viruses. Sometimes in the case of an inhibitor, a person's immune system reacts to proteins in factor concentrates as if they were harmful foreign substances because the body has never seen them before. When this happens, inhibitors (also called antibodies) form in the blood to fight against the foreign factor proteins. This stops the factor concentrates from being able to fix the bleeding problem.

Being in very hard to control is someone with hemophilia who develops inhibitors. A person with inhibitors faces more bleeding and pain because treatment with factor concentrates does not work. In patients with persistent inhibitors, if bleeding into the muscles and joints (the most common type of bleeding in hemophilia) is not controlled, permanent joint damage is likely.

For patients with sufficient access to care, treatment of inhibitors is one of the biggest challenges in hemophilia today. It is possible to get rid of inhibitors using a technique called immune tolerance induction. However, this type of treatment requires specialized medical expertise, is expensive, and takes a long time. Drugs called bypassing agents can be used to work around inhibitors and help blood clot.

What are inhibitors?

RELATED CONTENT



eLEARNING MODULE

WFH Guidelines for the Management of Hemophilia: Management of Inhibitors

Includes: 2 INTERACTIVE VIDEOS, 2 PDF DOCUMENTS AND 1 ASSESSMENT QUIZ



WEBCAST


Complications of Hemophilia: Inhibitors

Mr. James Mann 2009




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EDUCATIONAL RESOURCES FOR PATIENTS AND TREATERS




Panel discussion




Patient testimonials




State-of-the-art webcasts & ePosters




Live webinar



Updated monograph



Journal summaries



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WHAT CAN THE GLOBAL COMMUNITY DO?

This global issue needs global solutions

- Work together to find the answers we still need
 - International collaboration in research and surveillance
 - Participation in the WFH Epidemiological Research Program
- Improve access to diagnosis and treatment products to treat inhibitors
- Keep the community well informed of risks, new research, and treatment options



THANK YOU