



PARTNERS

**Improving Access
to Haemophilia Care**

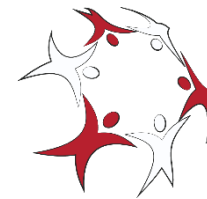
Amanda Bok
CEO
June 2019

EHC mission



1. Improve quality of life of people living with haemophilia, von Willebrands or rare bleeding disorders
2. Improve diagnostic and treatment facilities
- 3. Ensure adequate supply of – and access to – safe factor concentrates / therapies**
4. Promote patients' rights and raise ethical issues
5. Follow, influence developments in European health policy
6. Understand the status of haemophilia care in member countries through regular surveys

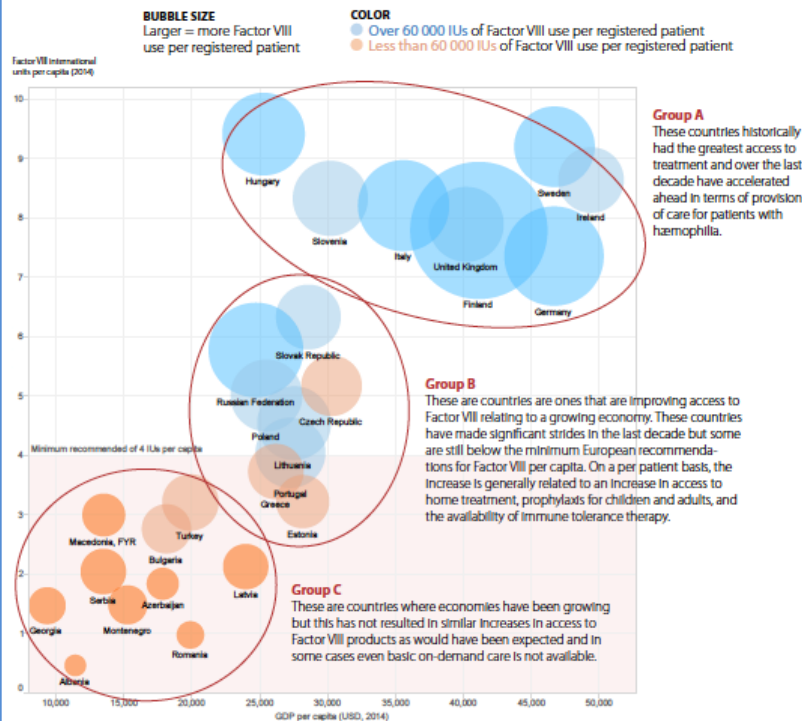
Haemophilia care in Europe: 7 years of access data



Significant disparity of access across Europe

The graph below summarizes the use of Factor VIII per capita compared to GDP per capita for each country that provided data for 2015. The graph highlights the significant difference in the amount of Factor VIII available in a country and compares this to GDP, which is used as indication of ability to pay. The size of the circles for each country represent the Factor VIII use based on reported registered patients. This is used to identify the access by those patients with haemophilia within each country to treatment and begin to understand the impact of a registry.

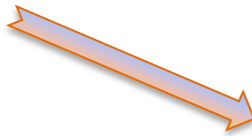
Overall, there is a clear disparity across Europe with three distinct groups developing. In the coming years there should be an emphasis on growing the Factor VIII per capita, Factor VIII per patient and the optimisation of Factor VIII use through registries to ensure equity across Europe for all patients. The disparity already present in the three groups should not increase.



Haemophilia care in Europe



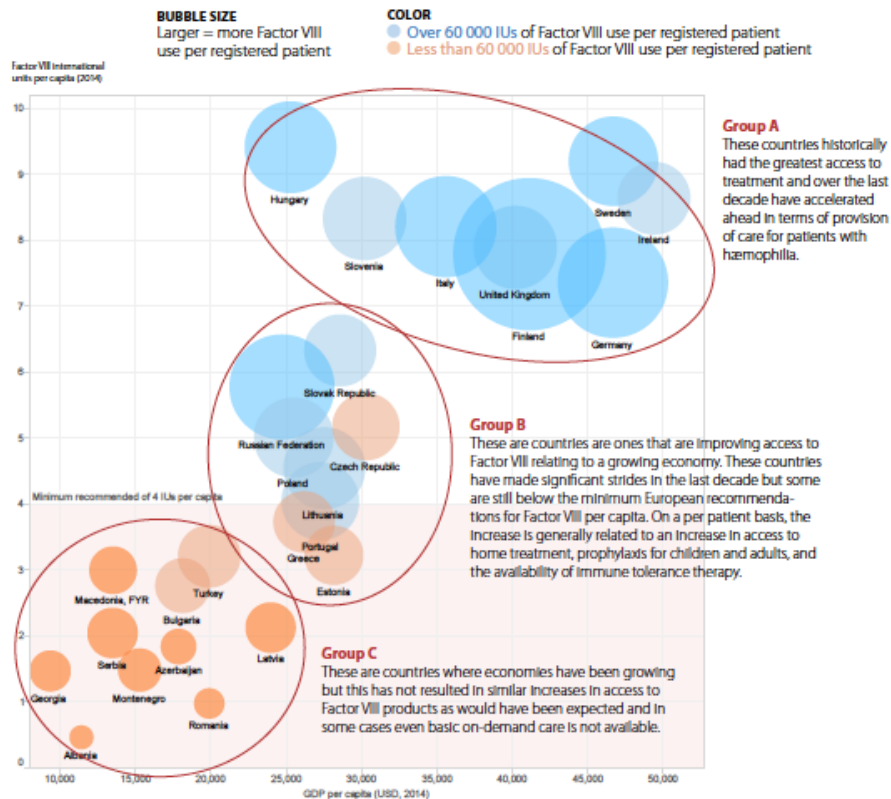
1. Albania
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3. Azerbaijan
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5. Bosnia-Herzegovina
6. Bulgaria
7. Estonia
8. Kyrgyz Republic
9. Latvia
10. Macedonia
11. Romania
12. Serbia
13. Turkey
14. Ukraine



Significant disparity of access across Europe

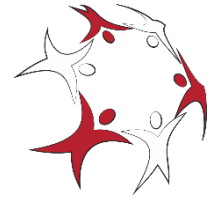
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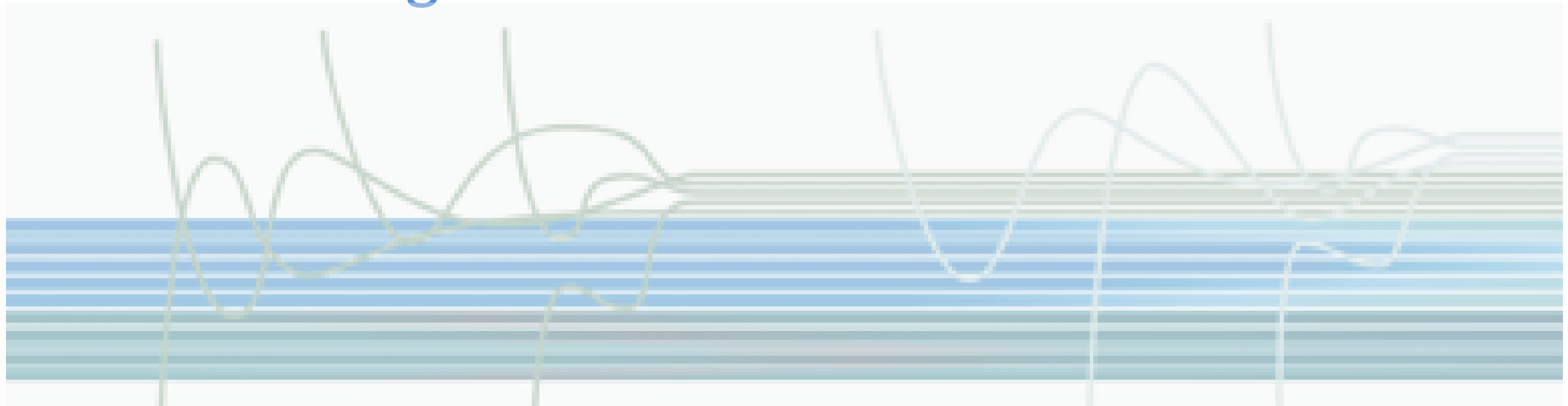
A bridging effort



Changed national procurement systems

Medium-term growth in national budgets

No immediate change to national budgets



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Objectives



- Enable countries to:
 - Provide adequate levels of treatment products
 - Improve access to treatment for PWH
 - Involve clinicians and patient representatives in procurement process
 - Improve treatment sustainability for healthcare systems

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Eligibility



- Countries where:
 - Current use of FVIII < 4 IU/capita
 - Current use of FIX < 0.5 IU/capita
 - Prophylaxis not available for all children w/severe
 - Governments + HCPs + NMOs + industry agree to participate
 - Governments agree to add HCPs + NMO on procurement body

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Commitment



- Governments agree to:
 - Use national-level procurement process for treatment products
 - Formally include clinicians and EHC patient representatives on long-term basis in process
 - Aim to award long-term contracts (ideally 3 years)
 - Increase product purchase w/o decreasing budget
 - At least double current purchase until min. IU standards are met

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Support & Oversight



- Endorsements & one MOU



- Overseen by multi-stakeholder advisory group
 - EHC Steering Committee
 - EHC Medical & Scientific Advisory Group
 - External legal & regulatory advisor
 - Representatives of participating manufacturers



PARTNERS to-date



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Progress Report

YEAR 1 (2018)





EHC
european haemophilia consortium

EHC PROGRESS REPORT ON PARTNERS – YEAR 1

The rising tide lifts all boats

The implementation of PARTNERS is divided into four stages across three phases of countries. As expected, we see the most progress in phase 1 countries, which are most advanced, and some in phase 2, where dialogue has begun. Work is in embryonic stages in Phase 3 countries.

LEGEND

In the river metaphor below, each indicator is represented by an affluent that reaches the main river to 'raise the tide' towards treatment levels recommended by the Council of Europe.

- Moving forward reliably
- Moving forward slowly
- In development

PHASE 1 COUNTRIES
Macedonia, Romania, Serbia, Ukraine, Kyrgyz Republic

STAGE 1
Dialogue and trust building

Improved willingness to innovate. a. Industry b. National governments c. Improved decision-making process

Improved trust and dialogue d. NMO-GOV e. NMO-GOV-EHC f. Improved stakeholder relationships

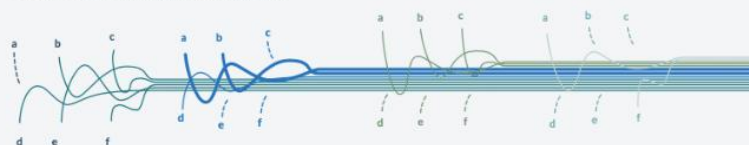
STAGE 2
Vision, education and empowerment

a. Improved patient expertise b. Improved patient impact c. Involvement of patient representatives in procurement

d. Improved patient-clinician education e. Improved patient-clinician empowerment f. Involvement of clinicians in procurement

PHASE 2 COUNTRIES
Albania, Azerbaijan, Bulgaria, Latvia

See Phase 1 above for the definition of the categories.



PHASE 3 COUNTRIES
Armenia, Belarus, Bosnia and Herzegovina, Estonia, Turkey

No progress to report yet.

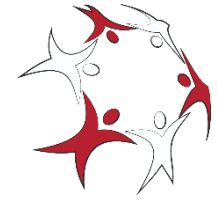
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Next steps



- Expansion of collaboration with UNDP
 - Azerbaijan, Armenia, Kyrgyz Republic
- Increased focus on clinician education
 - Medical videos coming soon
- Continued patient education
 - Procurement workshop in September 2019
- Three-year programme review

Status update

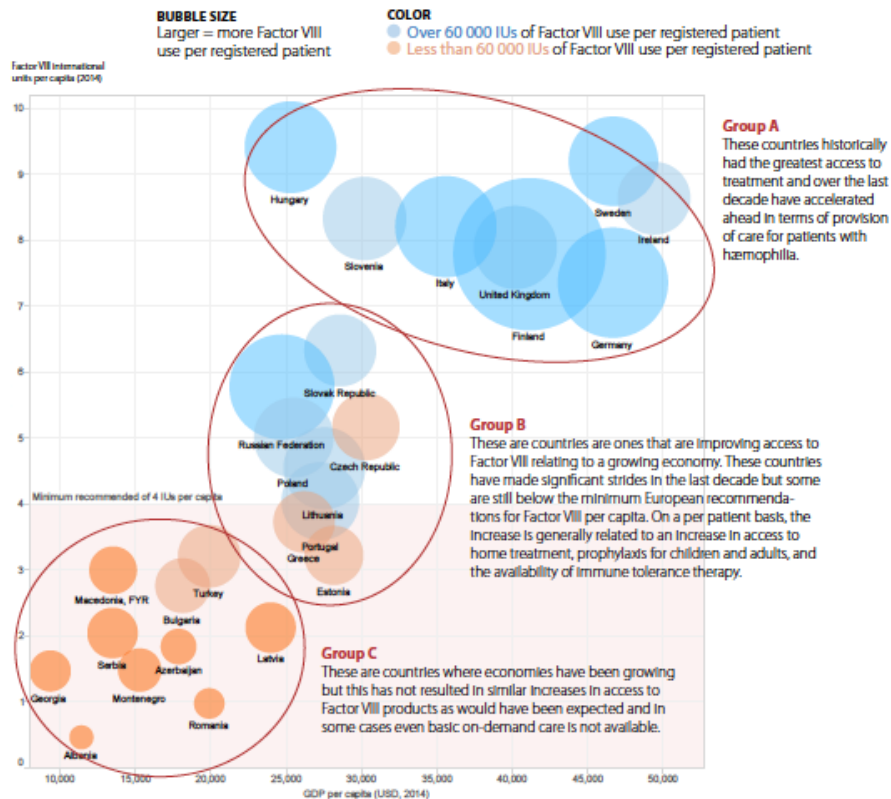


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14. Ukraine
15. Maybe: Moldova
16. Maybe: Tajikistan

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Thank you for your attention

