

# **Impact of non-involvement of patient organizations**

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# Scandinavia and Baltic states





# Estonia



Population - 1,340,415 (Tallinn 435 000)

# Hematology and Hemophilia Care

- North Estonia Medical Center
  - Blood Bank
- Tartu University Hospital
  - Blood Bank
- Tallinn Children's Hospital

Coagulation factors are reimbursed 100% by  
Estonian Health Insurance Fund

- Hospital based distribution system

# Procurement of coagulation factors

- Public Procurement Act
- Published in [ted.europa.eu](http://ted.europa.eu)
- Medicinal products for the blood and blood-forming organs
- Aim to use of surplus plasma for the production of plasma-derived medicinal products (albumin, IVIG, coagulation factors)
- Award criteria
  - Price weighting - 98
  - Ability to supply pathogen-reduced plasma - 2

# Impact of Tender Board Composition

- Appointed tender committee
  - No involvement on hematologists
  - No involvement of patient organization
- Product change complete surprise for treating physicians and patients
- Complaints about products
- Written explanation both by physician and patient for continuity of the same products
- Industry “Dear.....” letter!

# Impact to reimbursement - Trust

- Recombinant factors
- Application to the Health Insurance Fund
- Safety: plasma = recombinant
- No approval – Cost and the budget
- Family relationship between company contractor and the Health Insurance Fund Board member - patients concern about fair voting for competitor product
- Estonian TV “Pealtnägija”

## Impact beyond borders - EU

- The EHC president Mr. Brian O'Mahony's visit to Estonia in May 2013
- Meetings
  - NMO, Government, Health Insurance Fund, Medicines Agency, Hemophilia key physicians
- Prime time news in Estonian TV "Aktuaalne Kaamera"
- Conclusions: Exchange of information
- Outcome – EHC-WFH-EAHAD visit in 2015



# Changes in Tender Board

- One hematologist
- No patient organization involvement
- Specific indications for non-contractor product usage

# Request to open care prescription

- Closer to home
- Recombinant factors
- Open competition for pricing
- Industry “Dear.....” letter to Social Ministry and Health Insurance Fund
  - Negative impact of several million euros
  - Current set-up meets the needs
  - Warnings about switching the product
  - Sole supplier of one product with certain price level (false fact)
  - Cost increase of products (threat, false fact)

# Impact for pricing

- Increased costs for coagulation factors?

Product	Health Insurance Fund Prices, EUR/IU		
	2013	2014	2015
F VIII	0.329	0.292	0.329
F IX	0.54	0.525	0.54
F VII	0.412	0.412	0.477
aPCC	0.9	0.686	0.868

<https://www.riigiteataja.ee/akt/129122014055> §73.

**Ministry of Social Affairs is asking in open care prescription approval process to reduce prices at least to the level of reference countries**

**Tender – Recombinant F VIII max 0.329 EUR/IU**

# Impact of non-involvement of patient organizations - Conclusions

Non-involvement of patient organization has profound impact on:

- Trust in the Health Care System
- Trust in the fairness of The Reimbursement System and Process
- Trust in the Pharma Industry

Increase coagulation factors cost (?)

**THANK YOU!**



**Involvement of patient organization is critical!**