

# Step forward in health care for children with hemophilia in Republic of Macedonia

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## Introduction and Objectives

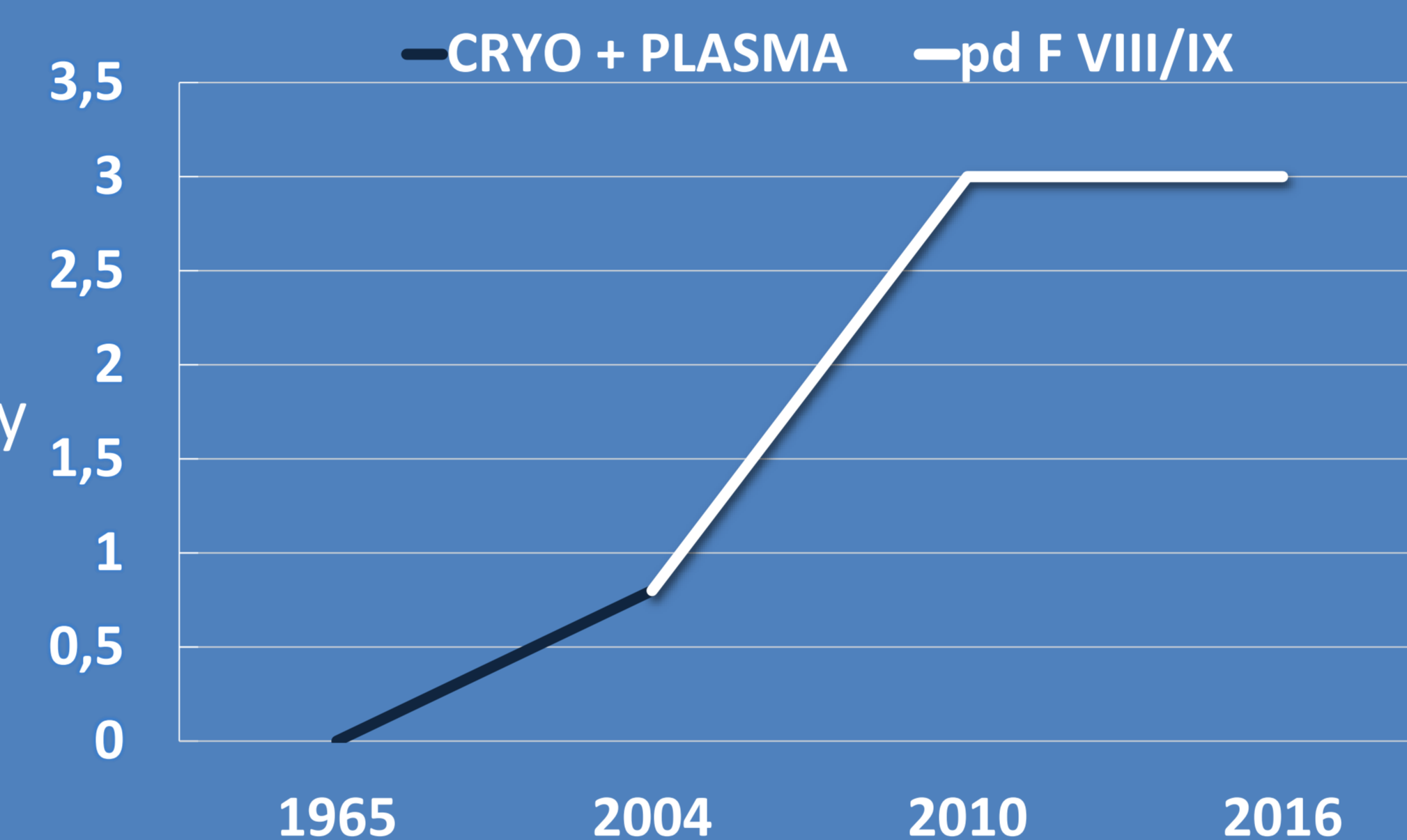
- Republic of Macedonia (RM) is South-Eastern European country with around 2 million inhabitants.



- University Children's Clinic in Skopje is a single institution where all children (0-18 years) with bleeding disorders in RM are diagnosed and controlled.
- Diagnosis of hemophilia was established in 1965, yet plasma and cryoprecipitate from voluntary donations were the only treatment until 2004.
- Factor concentrates (Pd) were introduced in 2004 in limited amounts. Prophylaxis for children with severe HA was introduced in 2007, for 4 small children.

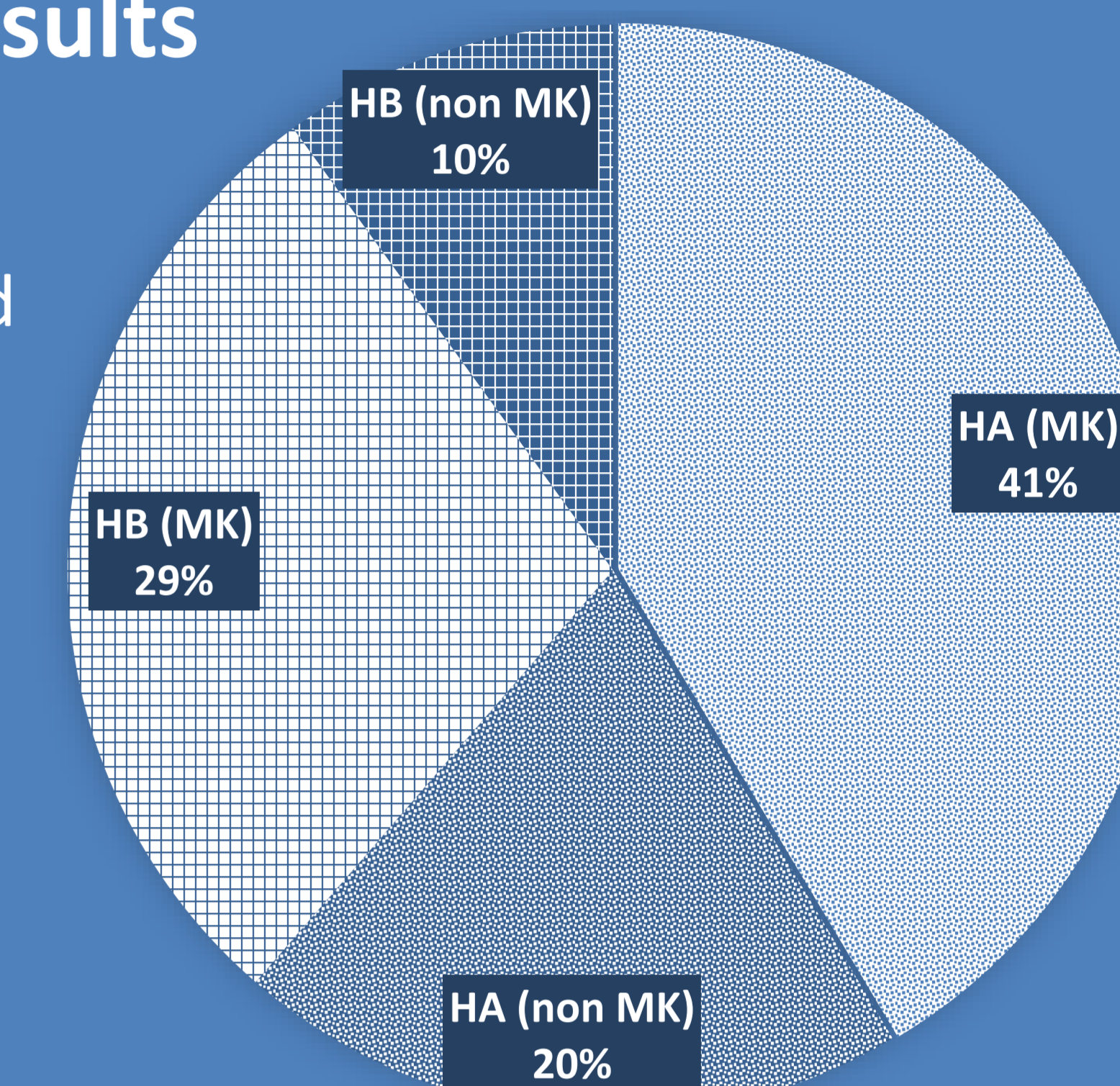
## Methods

- The excellent collaboration between health care professionals and Association of PWH on the project "Capacity Building of Hemophilia Health Care in Macedonia" NNHF/MK, sponsored by the Novo Nordisk Hemophilia Foundation, resulted in establishing National Hemophilia Register and Hemophilia Treatment Centre (HTC Skopje)- uniting functions of the Institute for Transfusion medicine, University Children's Clinic and Hematology Clinic.
- The standardization was made in collaboration with HTC Bonn, Germany in the "Twining program" setting.
- All these influenced health authorities to built National Strategy-Program for Haemophilia in RM, resulting in growing supply with factor concentrates (Pd).
- These allowed prophylaxis for all children with severe hemophilia. Factor concentrate consumption rose from below 1 IU to 3 IU per capita.
- Treatment with recombinant FVIII started 2010 in clinical study setting.



## Results

- Since 1965, 289 children with hemophilia were diagnosed (193 MK, 96 from surrounding countries, HA 197 (133 MK) and HB 92 (60 MK).
- One HA and one HB child developed inhibitors and they were treated with rFVIIa.
- Prophylactic home treatment was applied to 12 HA and 2 HB children and short term secondary prophylaxis for 10 (8 HA and 2 HB).
- There were performed tonsillectomy for 3, appendectomy for 1, circumcision for 5, synovectomy for 1 child and over 50 tooth extractions.
- Genetic diagnosis, genetic counseling and prenatal diagnosis are available.



## Conclusion

- Great improvement of the health care for children with hemophilia in RM was achieved in the last 10 years.
- HTC Skopje was equipped with multidisciplinary team.
- In 2014 HTC Skopje was recognized as Comprehensive HTC

## References

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- GUIDELINES FOR THE MANAGEMENT OF HEMOPHILIA 2nd edition Prepared by the Treatment Guidelines Working Group, on behalf of the World Federation of Hemophilia (WFH) Dr. Alok Srivastava (Chair) Dr. Andrew K. Brewer, Dr. Eveline P. Mauser-Bunschoten, Dr. Nigel S. Key, Dr. Steve Kitchen, Dr. Adolfo Llinas, Dr. Christopher A. Ludlam, Dr. Johnny N. Mahlangu, Kathy Mulder, Dr. Man-Chiu Poon, Dr. Alison Street.

