HemoNED
Dutch Hemophilia Registry

MONITORING OF EMICIZUMAB USING A PATIENT REGISTRY

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https://hemoned.nl/en/

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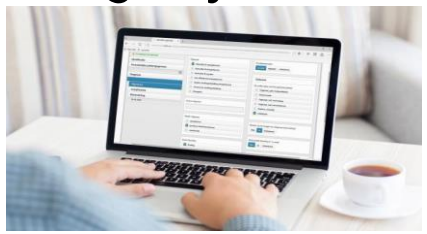
Introduction

Emicizumab is available in the Netherlands since August 2020

Monitoring of new expensive medicines by patients registries is encouraged by EMA

Aim

Evaluate the use and and outcomes of emicizumab, using the Dutch Hemophilia Registry (HemoNED)



Methods

Patients with Hemophilia A from all 6 Dutch HTCs included in HemoNED in July 2021

Treatment plans, digital infusion log data (infusions and bleeds), adverse events

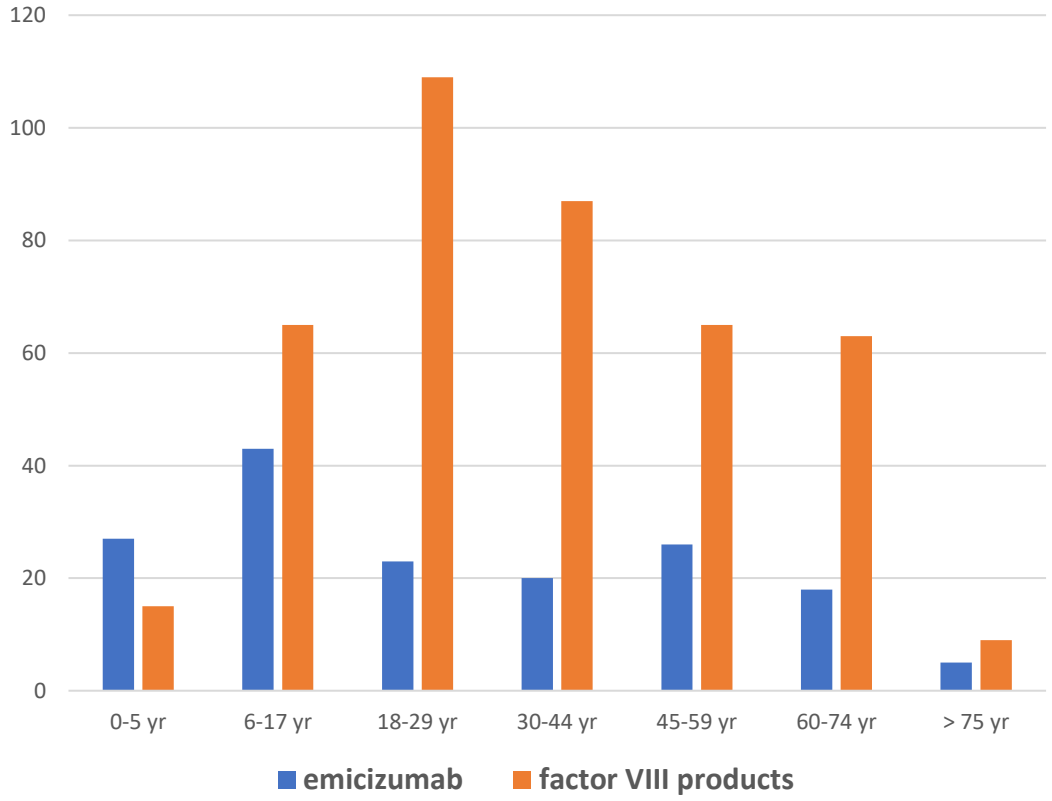
Results

1333 Hemophilia A patients, 575 on prophylaxis

162 patients emicizumab

RESULTS: EMICIZUMAB IN HEMONED

Age categories of Hem A patients on prophylactic treatment (N=575)



Main reason to start emicizumab (N=142)

	N	%
Patient preference	74	52%
Venous access problems	22	15%
Inhibitor with bleeding tendency	17	12%
Recurring bleeds despite regular prophylaxis	13	9%
Not being able to administer regular prophylaxis	9	6%
Very active life (sports, travelling)	7	5%

Results and Conclusion: emicizumab in HemoNED

Treatment plan

> 80 % emicizumab 1x / 1-2 weeks; mean dose 1,6 mg/kg/week

Outcomes (digital infusion logs)

119 patients, 92 patients (77%) reported no bleeds

3 patients reported side effects (rash, joint pain)

Conclusion

A patient registry & infusion log could provide real world data

Quality of data and burden of registration needs attention

Thanks to all Dutch Hemophilia Treatment Centers and Dutch Hemophilia Patients Society