

aHUS: resultaten van de CUREiHUS studie

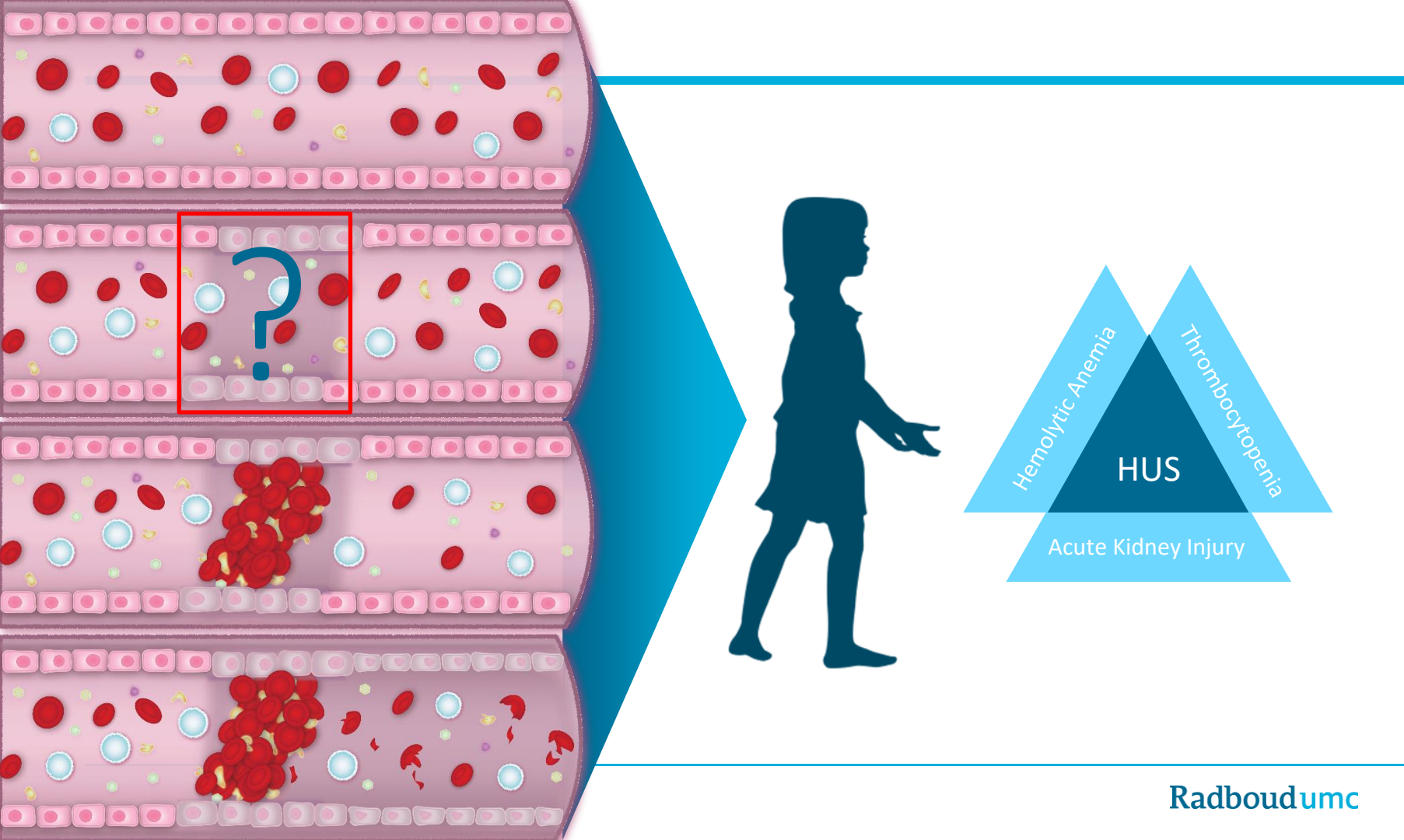
Romy Bouwmeester
Caroline Duineveld

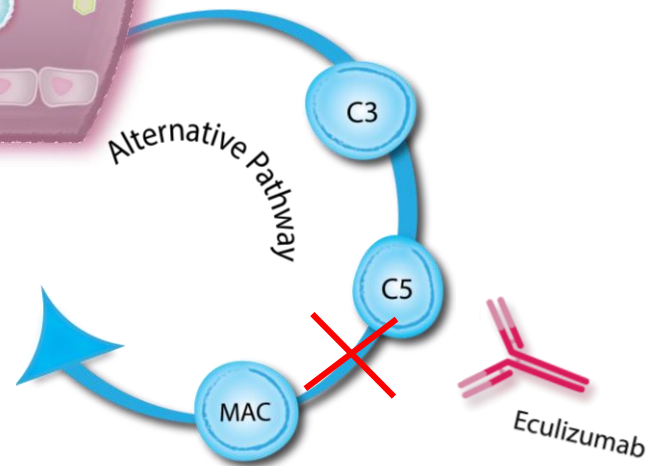
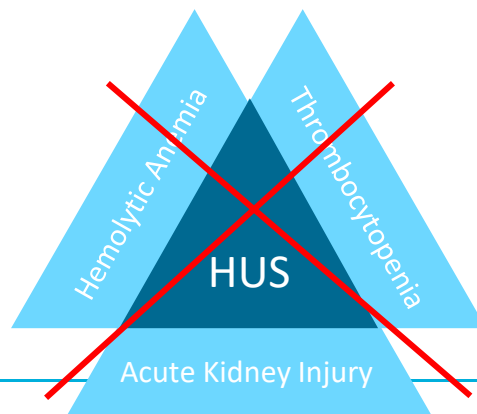
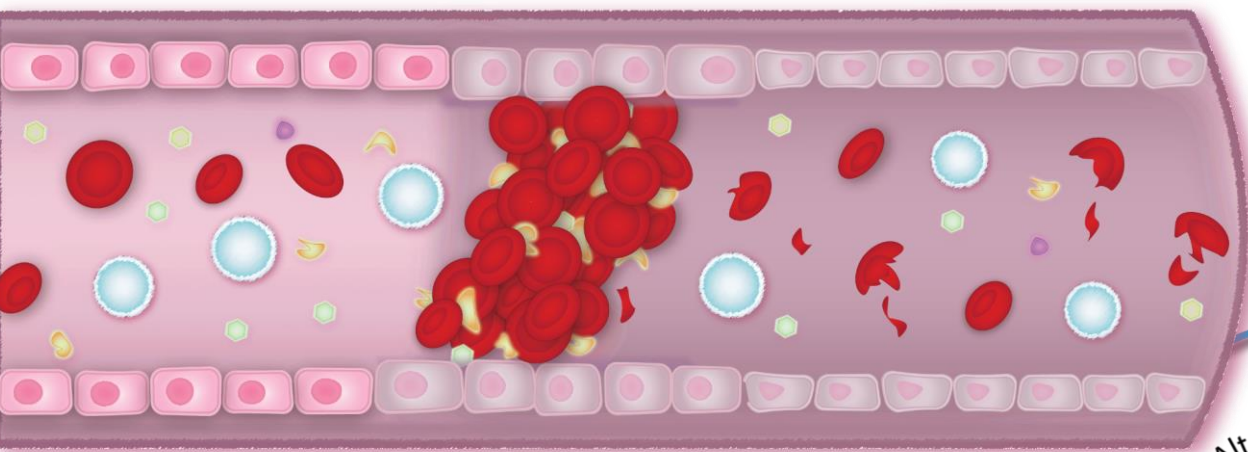


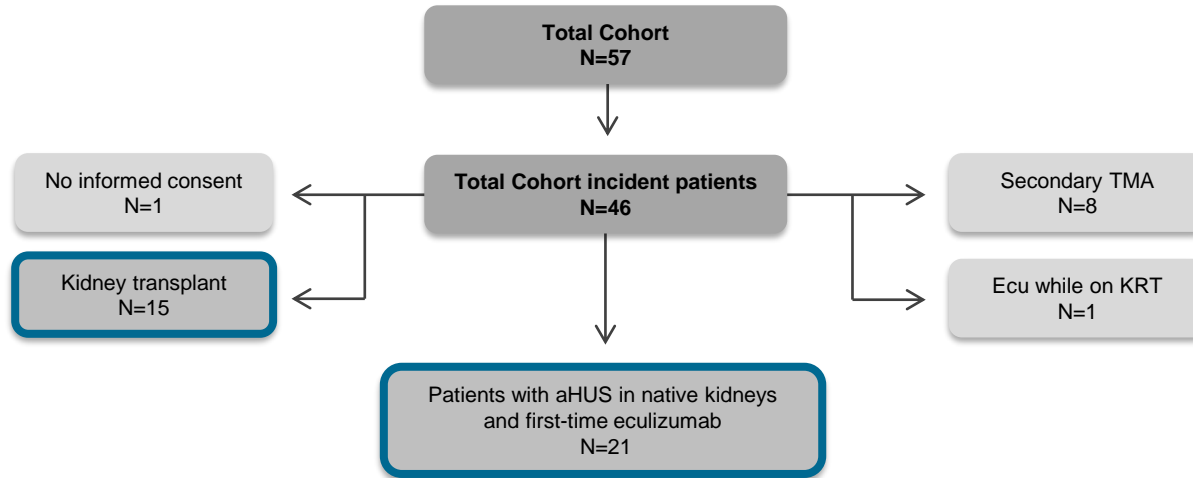
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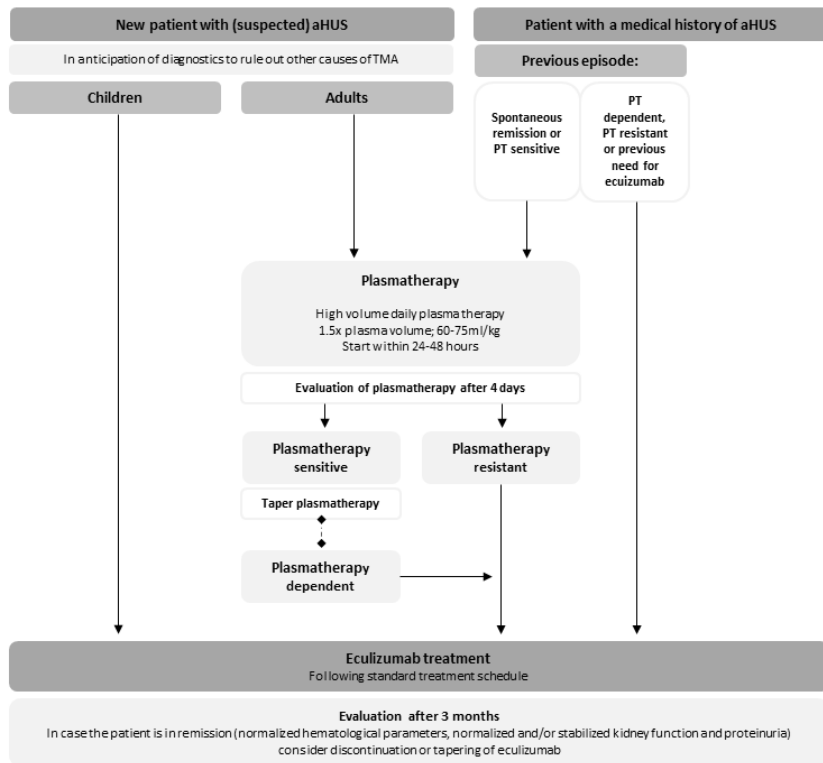
Disclosure

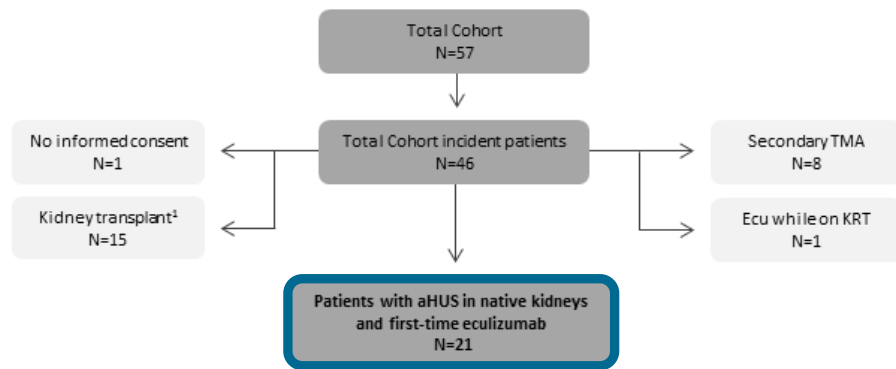
(potentiële) belangenverstrengeling	Geen
Voor bijeenkomst mogelijk relevante relaties met bedrijven	
<ul style="list-style-type: none">• Sponsoring of onderzoeksgeld• Honorarium of andere (financiële) vergoeding• Aandeelhouder• Andere relatie, namelijk ...	

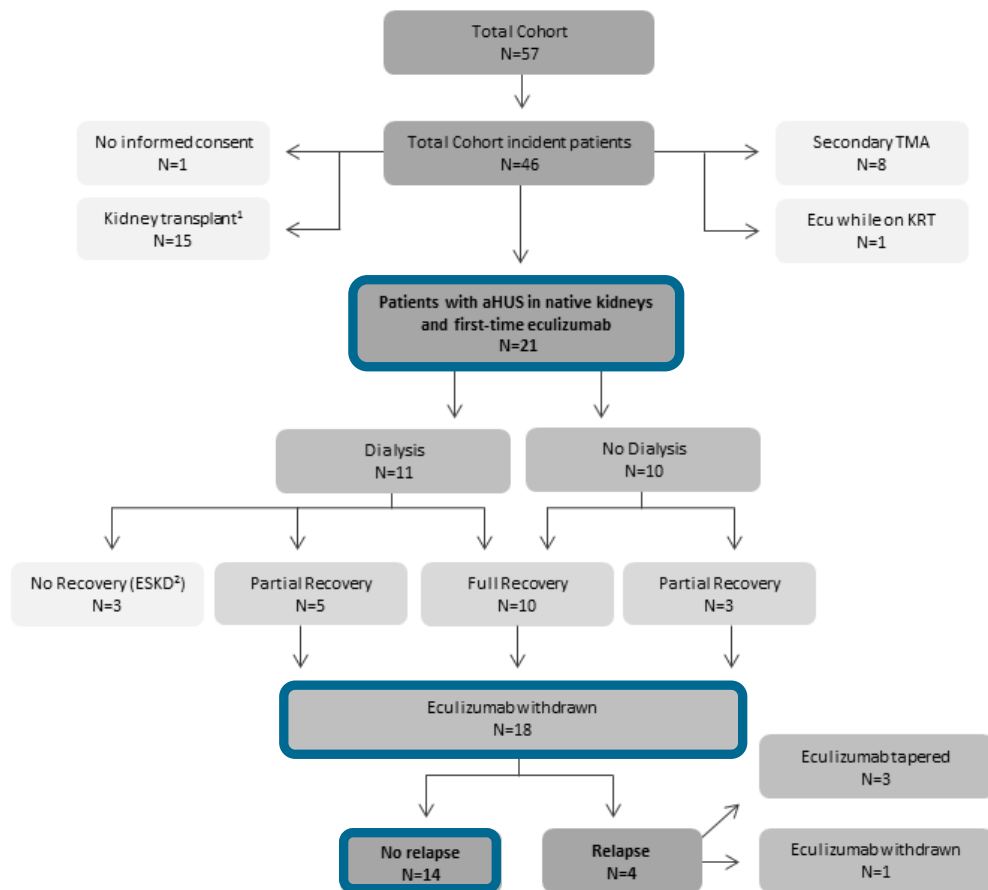










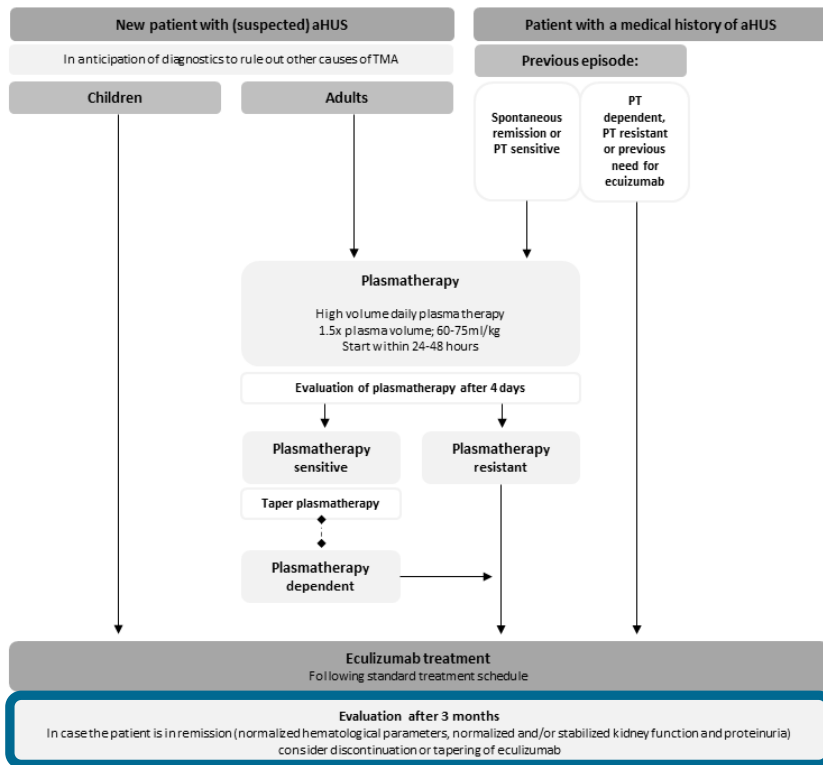


Flow-chart of eculizumab therapy and outcomes in CUREiHUS incident patients with native kidneys

Author (et al) Year of publication	Cohort discount* *Children Ntx	Eculizumab treatment Range	Follow-up duration Range	Relapse Rate n=	Time to Relapse Range	Outcome Relapse
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<i>Retrospective studies</i>		Total/Mean				
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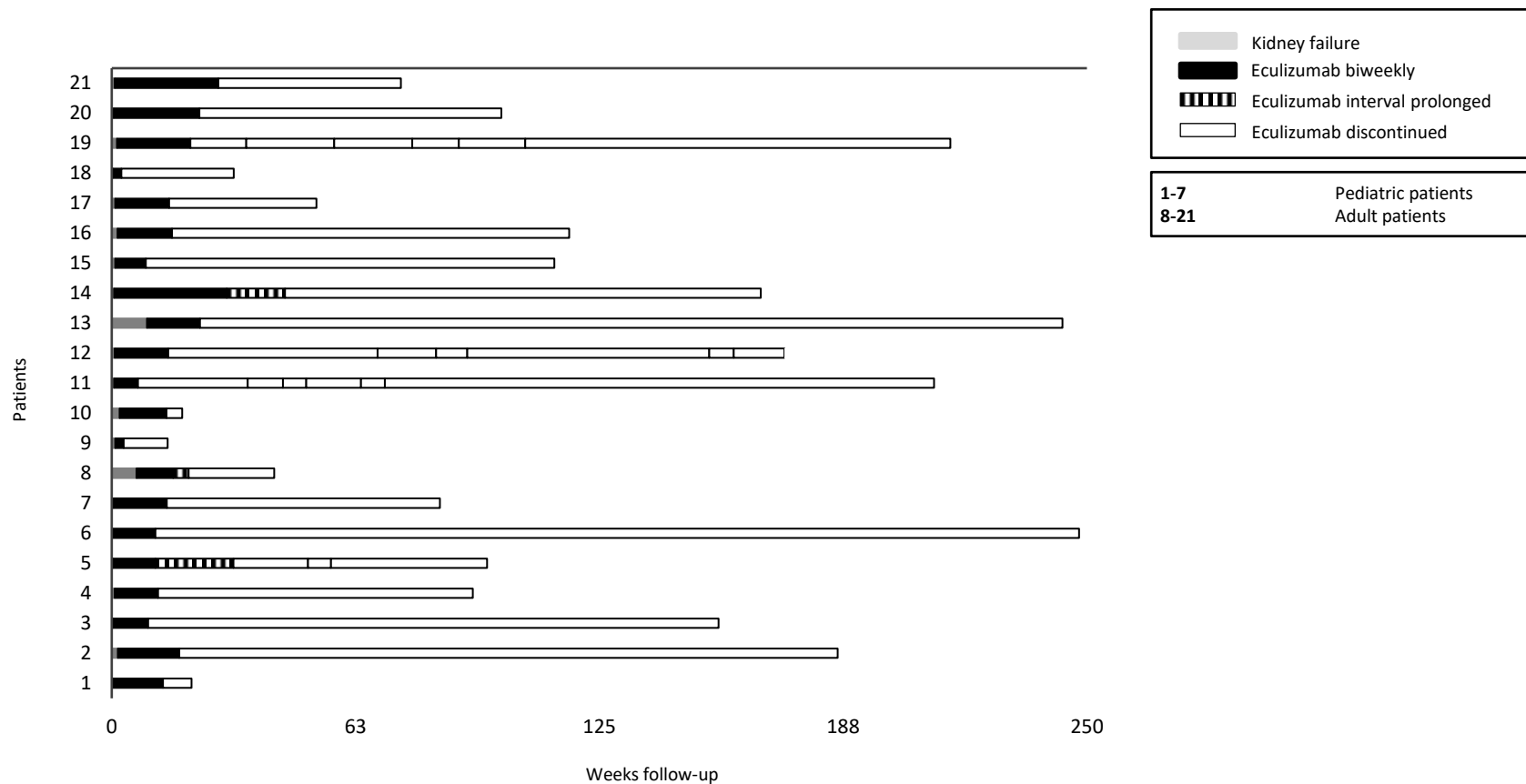
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Unbiased!

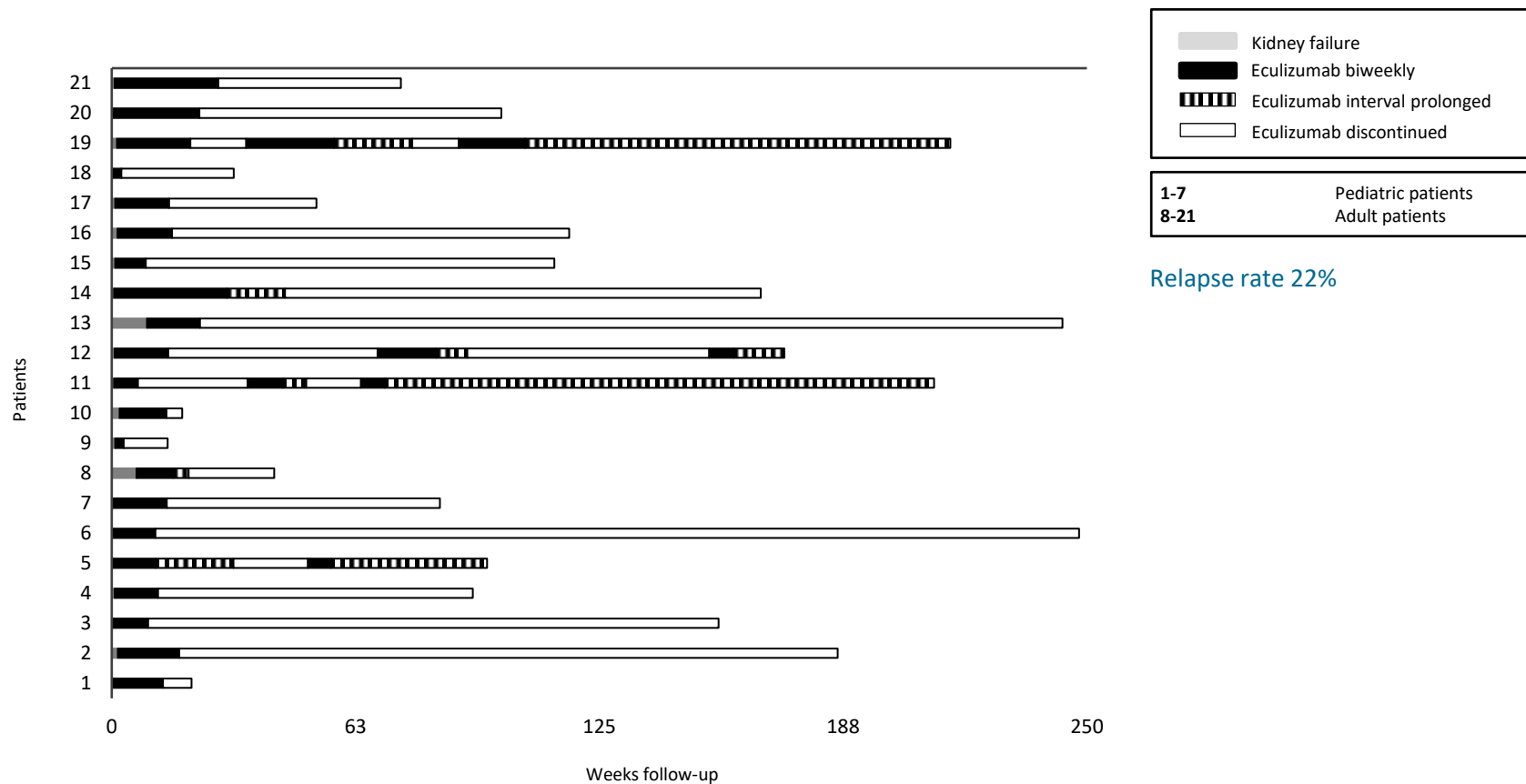
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Median follow-up duration: 99.9 weeks (14.3-248.0)

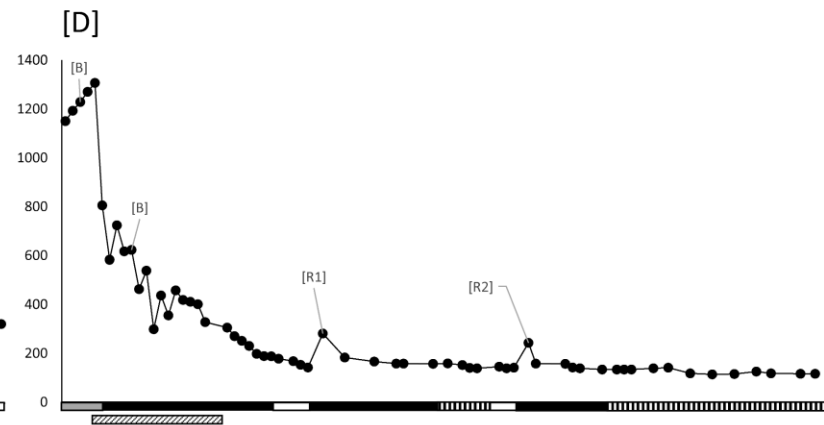
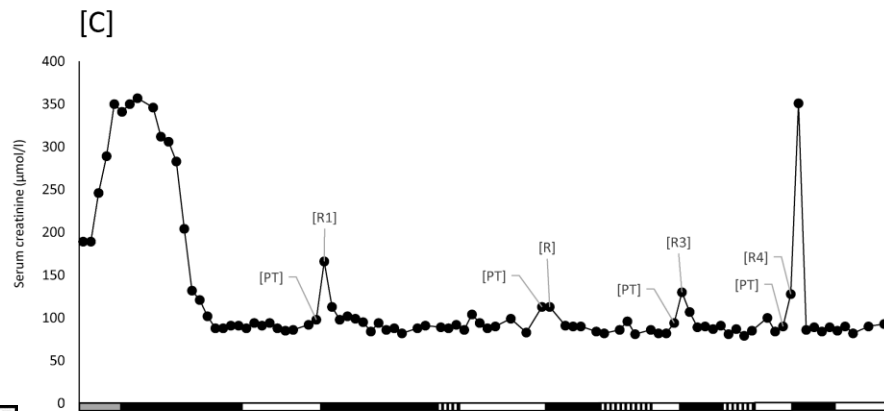
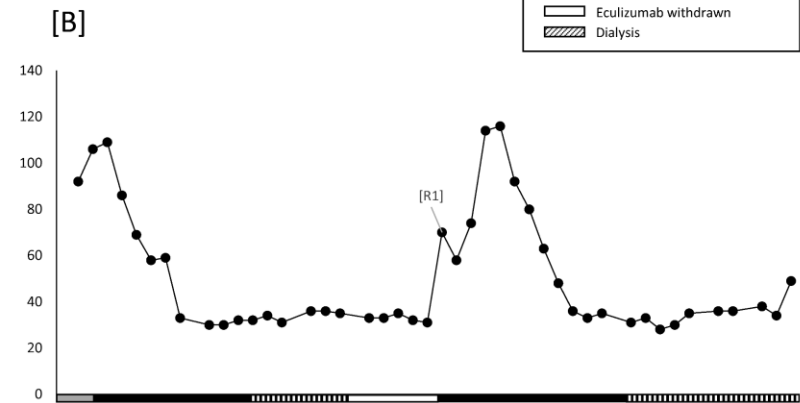
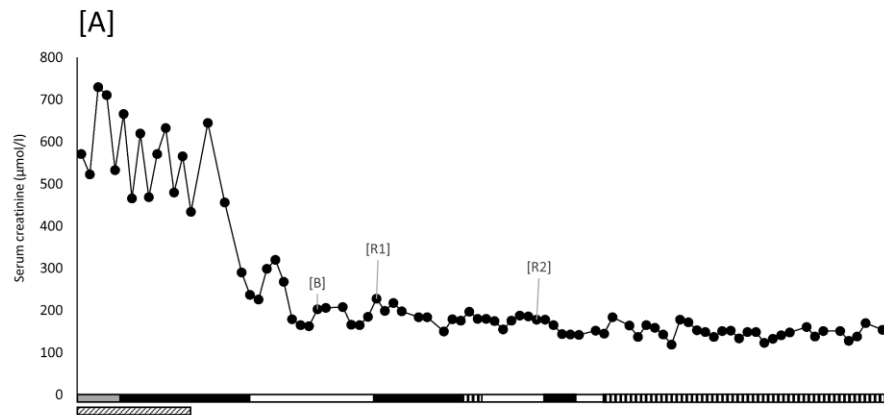
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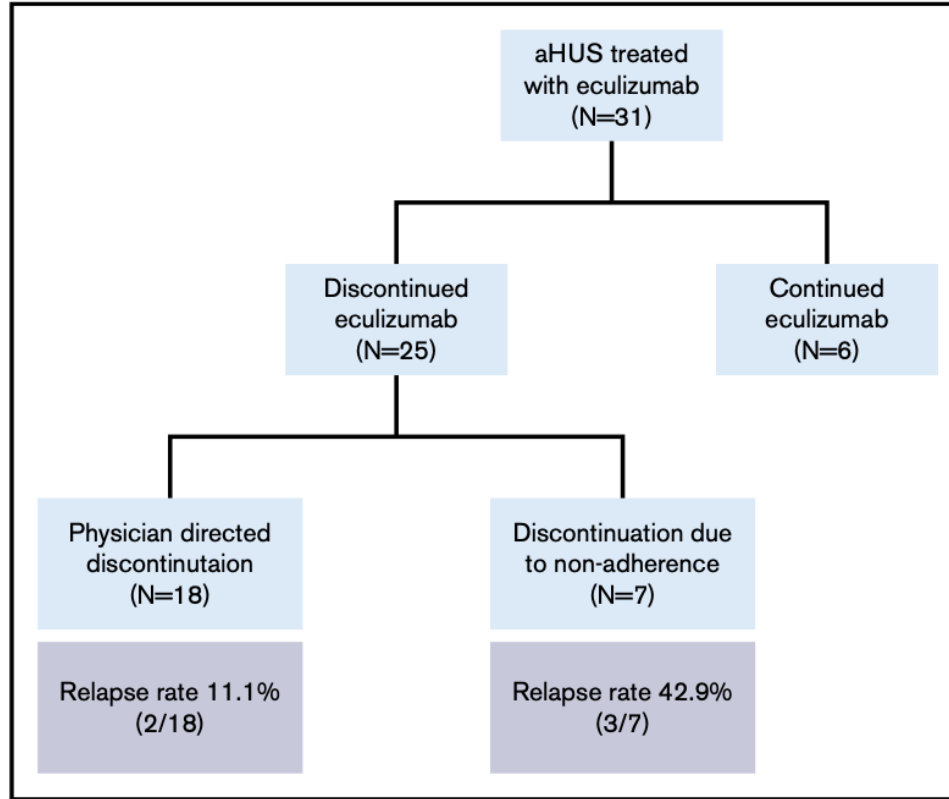
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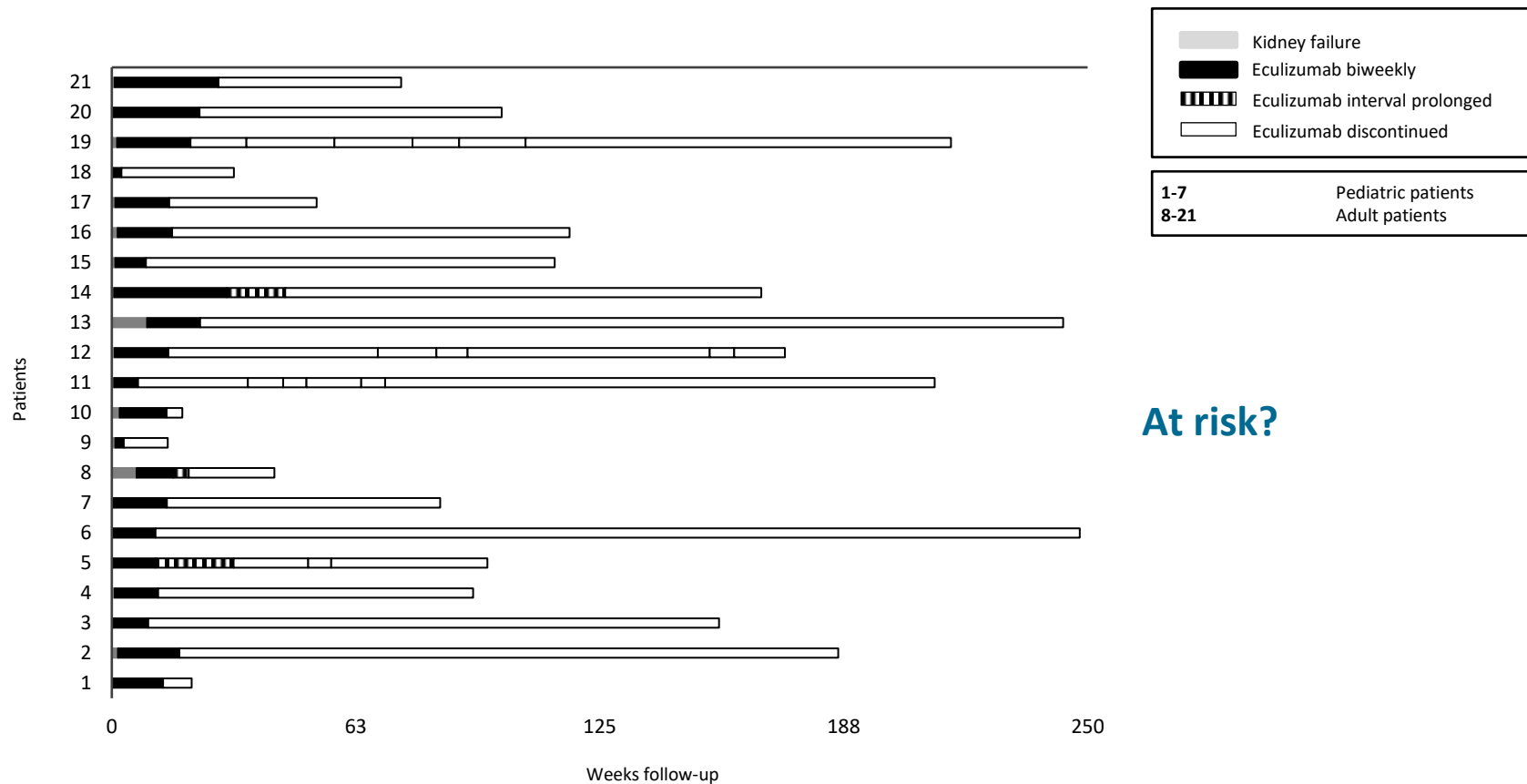
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Serum creatinine concentrations over time in the 4 relapsing patients
Bouwmeester et al. KIR. 2022

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At risk?

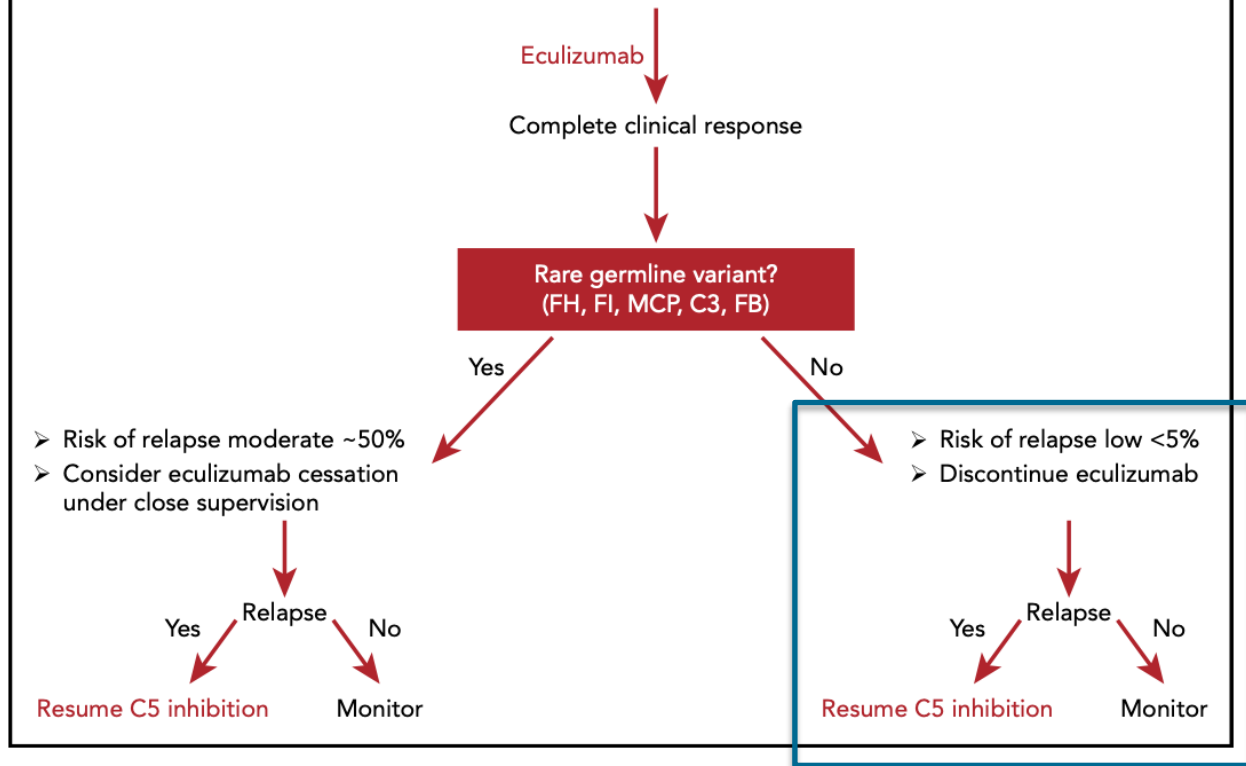


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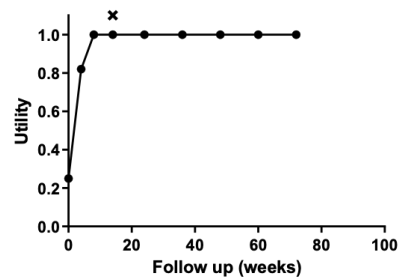
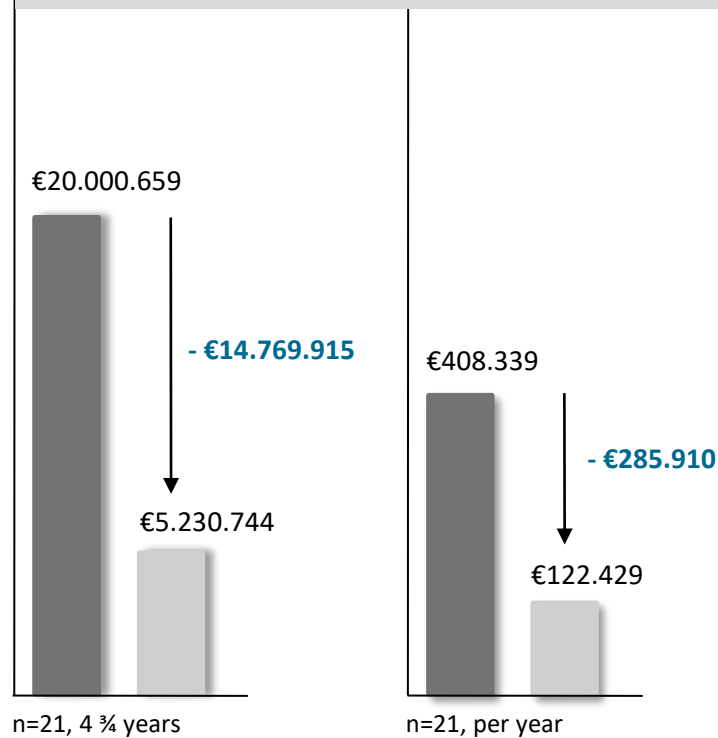
Relapse Rate			
Female	64%	Male	21%
Child	63%	Adult	35%
CFH or MCP variant	50%	Other genetic variant	30%
No extra-renal manifestation	56%	Extra-renal manifestation	20%
sC5b-9 $\geq 300\text{ng/ml}$	58%	sC5b-9 $< 300\text{ng/ml}$	11%



Atypical hemolytic uremic syndrome



Patients with aHUS in native kidneys



Practice Points

Outcomes discontinuation

- **SAFE and COST-effective**
- No negative influence on quality of life
- **Majority of relapses:**
 - <1 year after discontinuation
 - CFH most common in relapse and non-relapse group
- **Risk factors:** clinical relevance?

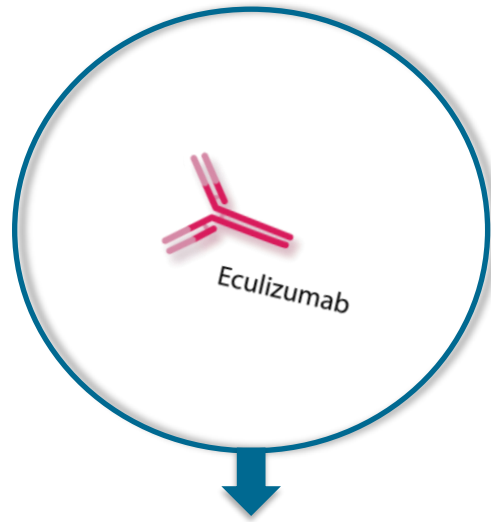
Future perspectives

Larger data registries:

- Unbiased discontinuation
- Longer follow-up: long-term risks?

Biomarkers early detection of disease activity

Other complement inhibitors?



Add-on indicatie



Samen met Nierpatiënten-vereniging & Landelijke aHUS werkgroep

