

### Dear colleagues,

We are delighted to present you the latest edition of the Carotid Aneurysm Registry (CAR) newsletter. You are receiving this newsletter because of your prior interest and/or collaboration with our research group.

Our mission to assemble patients with an extracranial carotid artery aneurysm (ECAA) started in 2014. In the past decade, multiple national and international centres, have joined forces with us on this important mission. Now the COVID-pandemic with all inherent restrictions is behind us, we are enthusiastic about the opportunity to reengage with our (inter)national partners, including yourself, in our research efforts.

Per January first, Saskia Willemsen had hand over the daily coordination to Roos van Heeswijk. We would like to thank Saskia for her dedication and contribution to the registry.

In order to achieve our goal of a better understanding of this rare condition, we will continue our efforts to collect and share knowledge and in expanding our registry by including new patients and collect long term follow-up on well phenotyped patients.

In this newsletter, you will find updates on the latest developments and progress made by the registry. We are grateful for your contributions and hope that it will inspire further collaboration to improve the care of patients with ECAs.

Yours sincerely,

Roos van Heeswijk,

Prof. dr. Gert. J. de Borst

### Main goal & Mission

Aneurysms of the extracranial carotid artery (ECAAs) are rare, often discovered during a routine imaging scan in asymptomatic patients. However, symptoms such as local cervical compression and cerebral thromboembolization can occur. The main goal of the CAR registry is to collect and share knowledge obtained from clinical and imaging data of patients with an ECAA. Any patient with an ECAA can be registered, regardless of symptoms or treatment choice.

Ultimately, we hope that our research will lead to a foundation for treatment guidelines of this rare vascular disease.

### Contact Information

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### Number of Inclusions

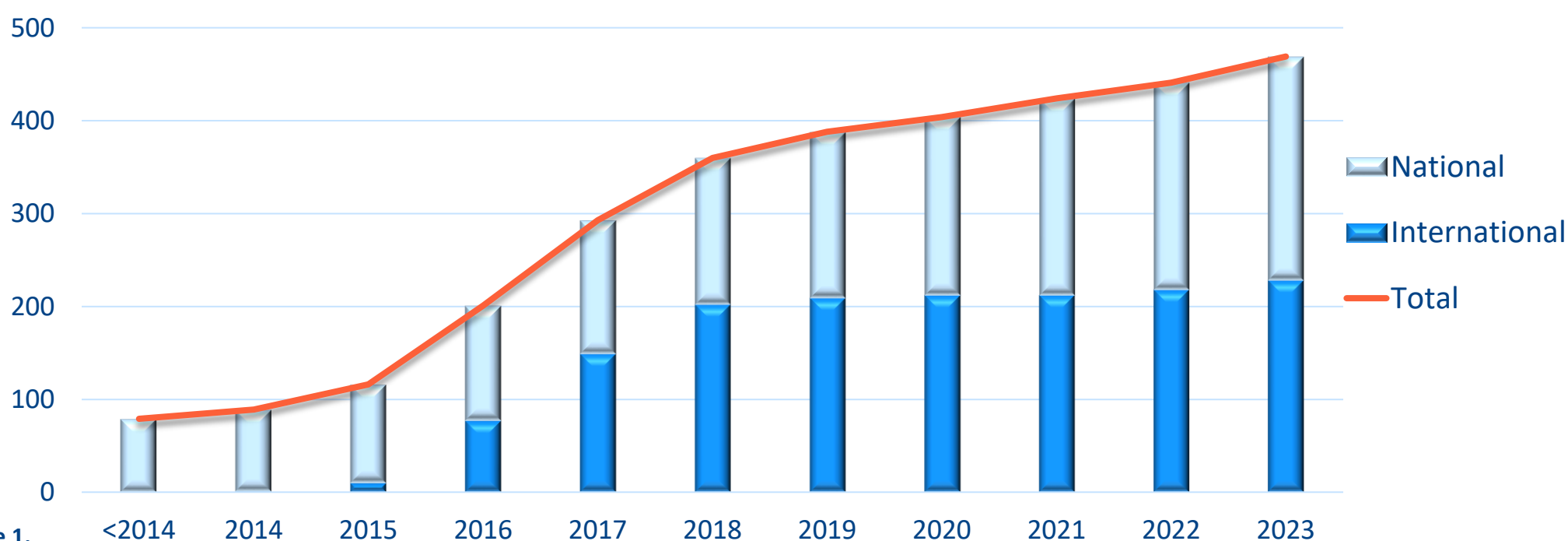


Figure 1.

### Inclusion of New Patients

Since 2019, our team has been collecting data on ECAA patients through the Castor EDC platform. Factors such as new legislations requiring data contracts, the submission of patients in clusters, transitioning from the web-based registry to Castor, and the COVID-19 pandemic have contributed to a slowdown in inclusions from international centers, as illustrated in Figure 1: Number of Inclusions. We hope to resume previous collaborations and reach out to new centers to continue expanding the registry. To ensure smooth access to the Castor data platform and maintain the security of our study, we have implemented 2-Factor Authentication (2FA) for all users. How to set up 2FA:

- 1. Install Authentication App:** make sure you have an authentication app installed and updated on your phone/tablet
- 2. Access Your Account Settings:** Log in to your Castor account and navigate to 'Settings', then 'Password & Security'
- 3. Enable 2FA:** under the 'Two-factor authentication' section, tick the box for 'Using two-factor authentication with this account', then click the blue button 'Activate two-factor authentication'
- 4. Follow On-screen Instructions:** simply follow the instructions provided on your screen to complete the set up process.

If you encounter any difficulties setting up 2FA or accessing the platform, or if you wish to include patients for the first time, please sent an email to: [r.a.m.vanheeswijk@umcutrecht.nl](mailto:r.a.m.vanheeswijk@umcutrecht.nl)



### Data Update

The CAR currently includes **471 patients**, containing complete baseline and follow-up data of 243 Dutch patients and 228 international patients from 16 different nationalities.

Dutch patients are more often treated conservatively, with or without antithrombotic medication, whereas international patients more often have had surgical interventions, with an increasing preference for endovascular procedures.

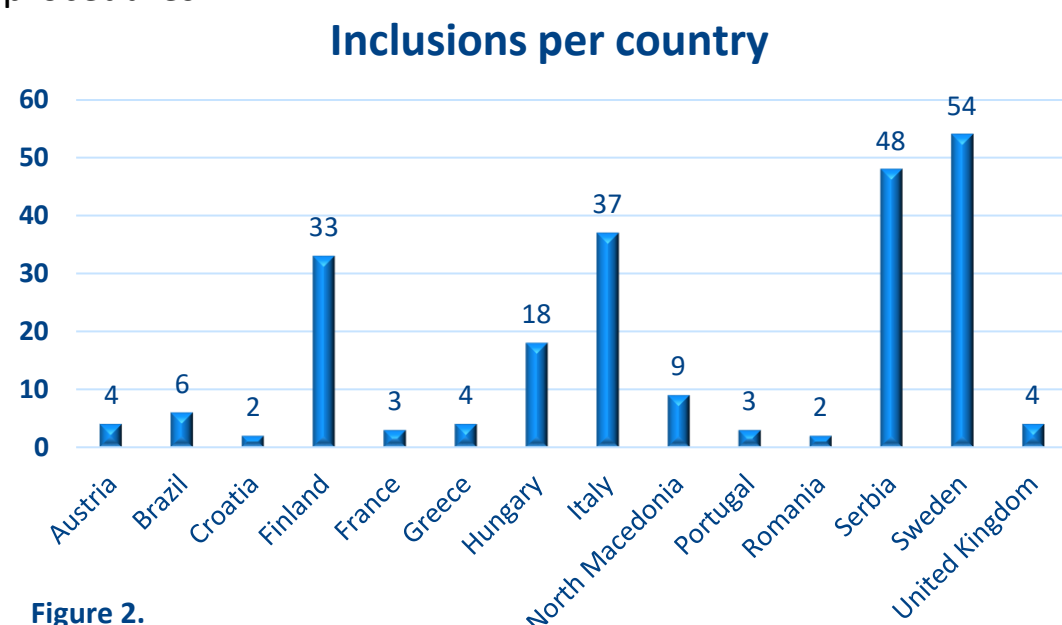


Figure 2.

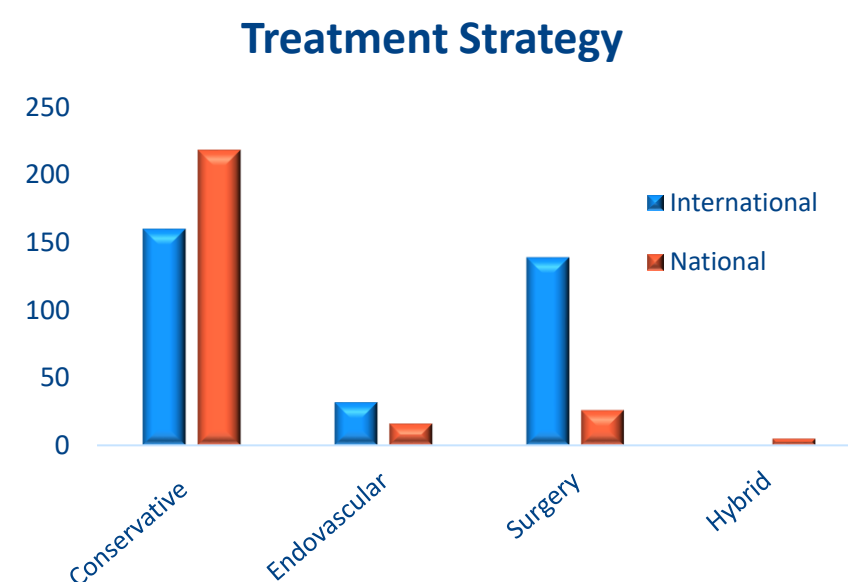


Figure 3.

### New Literature

- *vLaarhoven et al. Carotid tortuosity is associated with extracranial carotid artery aneurysms. QIMS 2022. PMID: 36330172*
- *vLaarhoven et al. Delayed development of aneurysmal dilatations in patients with extracranial carotid artery dissections. European Journal of Endovascular Surgery 2022. PMID: 35977695*
- *vLaarhoven et al. Co-prevalence of extracranial carotid aneurysms differs between European intracranial aneurysms cohorts. PLoS One 2020. PMID: 31971973*

### What the future holds

We are currently focusing on technical success and long-term outcomes of endovascular treatment. Additionally, our ongoing efforts include an imaging study aimed at investigating cerebral small vessel disease in patients treated conservatively.