

Do's and Don'ts Factsheets

for Rare Vascular
Disease Care in
Frequent Situations

For Patients

Hereditary
Hemorrhagic
Telangiectasia

Long Flights







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Introduction

This fact sheet has been developed by the members of the VASCERN Hereditary Hemorrhagic Telangiectasia (HHT) Working Group to provide important recommendations for managing long flights for patients with HHT. It is designed for both patients and caregivers. Long flights can present specific risks and challenges for individuals with HHT, and following these recommendations can help promote a safer and more comfortable travel experience.

The HHT WG endorses these recommendations, which have been made by consensus at the expert level. We encourage you to use this fact sheet as a reference and to consult with your physician to ensure the best possible care tailored to your individual needs.





Do's and Don'ts for Long Flights with HHT



WHAT IS RECOMMENDED

- As recommended for the general population, wear thromboembolic deterrent stockings (TEDs) during long flights.
- Stay hydrated during flights: Drink enough.
- Continue to take your regular medication while flying, especially if you use any kind of anticoagulation therapy.
- Be sure to take a walk on a regular basis during the flight.
- Make sure you have good advice for preventing or stopping a nosebleed, especially if you have to take anticoagulation.



WHAT YOU SHOULD NOT DO

- Forget to apply the nasal ointment/cream/temporary nasal occlusion that works for you before and during the flight.
- Forget to bring the devices and packing you normally use to treat nosebleeds with you in the cabin.





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VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, is dedicated to gathering the best expertise in Europe in order to provide accessible cross-border healthcare to patients with rare vascular diseases (an estimated 1.3 million affected). These include arterial diseases (affecting the aorta to small arteries), arterio-venous anomalies, vascular malformations, and lymphatic diseases.

VASCERN currently comprises 48 expert teams from 39 highly specialized multidisciplinary HCPs, plus 6 additional Affiliated Partner centers, coming from 19 EU Member States, as well as various European Patient Organisations, and is coordinated in Paris. France.

Through our 6 Rare Disease Working Groups (RDWGs) as well as several thematic WGs and the ePAG - European Patient Advocacy Group, we aim to improve care, promote best practices and guidelines, reinforce research, empower patients, provide training for healthcare professionals and realize the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

More information is available at: www.vascern.eu

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